THE EVALUATION OF THE VASCULAR DISEASE SELF-MANAGEMENT INSTRUMENT FOR ADULTS RECEIVING IN-CENTER/SATELLITE AND HOME HEMODIALYSIS: A FEASIBILITY STUDY

THE EVALUATION OF THE VASCULAR DISEASE SELF-MANAGEMENT INSTRUMENT FOR ADULTS RECEIVING IN-CENTER/SATELLITE AND HOME HEMODIALYSIS: A FEASIBILITY STUDY

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The evaluation of the vascular disease self-management instrument for adults receiving in-center/satellite and home hemodialysis: A feasibility study

Abstract

Background. A reliable and valid instrument printed in English that measures self-management for adults with vascular diseases receiving hemodialysis therapy was not found in the literature. The Vascular Disease Self-Management Instrument (VSMI) was developed to support the measurement and assessment of self-management.

Objectives. The primary objective was to assess the feasibility of the study methods to develop and explore the psychometric properties of the Vascular Disease Self-Management Instrument (VSMI) for adults receiving hemodialysis therapy. Feasibility outcomes included recruitment, consent and completion rates. The secondary objective was to begin to explore the reliability (internal consistency and test-retest), and construct validity using exploratory factor analysis and criterion-related validity.

Method. This feasibility study used seminal work (Thabane et al., 2010) and clinical expertise to determine feasibility outcomes. Examination of psychometric properties was based on Streiner & Norman (2008).

Results. Of the 267 eligible patients, a total of 136 patients were recruited into the study. The consent rate was 51% and completion rate was 32% for the test-retest analysis. Study participants were primarily male (61%), diagnosed with chronic kidney disease for 12 years and receiving hemodialysis therapy for 6 years. Half (50%) the participants were at moderate risk for psychological distress and used avoidant-oriented coping. Preliminary psychometric analysis suggested good reliability (Cronbach's alpha = 0.945) and stability

(Intraclass correlation coefficient = 0.927, p <0.0001). The results of the exploratory factor analysis indicated four main factors comprised the self-management instrument including collaborative partnerships, self-advocacy, self-monitoring and normalcy. Preliminary evidence of criterion-related validity demonstrated a significant positive relationship between task-orientated coping and self-management.

Conclusion. Feasibility outcomes were successfully met. Preliminary evidence suggests that the VSMI has the potential to become a reliable and valid instrument. A full-scale psychometric evaluation with a sample that includes adults receiving peritoneal dialysis is needed to support utilization of the VSMI in research and clinical practice.

The evaluation of the vascular disease self-management instrument for adults receiving in-center/satellite and home hemodialysis: A feasibility study

Lay Abstract

Background: Adults receiving dialysis therapy must engage in self-management of their illnesses. A questionnaire on self-management activities based on the individuals' experiences would help health care providers to identify areas where people struggle. This information could be used to develop programs that support self-management.

What Did We Learn: A total of 136 people took part in the study. The development and testing of a self-management questionnaire for adults undergoing hemodialysis is a worthwhile and reasonable goal. The questionnaire provided people with the opportunity to describe their self-management activities. Half the people that participated in the study were at risk for experiencing anxiety and depression and tried to avoid stress.

Conclusions: The questionnaire would assist health care providers to engage in future research projects and develop programs and resources that help people more independently manages their illnesses.

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CHAPTER 1

Introduction

Why is Self-Management Important For Those Receiving Hemodialysis Therapy?

Adults with end-stage renal failure receiving hemodialysis therapy are often diagnosed with other vascular diseases (heart disease, hypertension, diabetes) placing considerable burden on scarce health care resources (Manns, Mendelssohn & Taub, 2007). Efforts to address this growing concern have generated significant interest in self-management behaviors and their potential to reduce in-hospital healthcare costs and improve patient outcomes (Bodenheimer, Lorig, Holman & Grumback, 2002; Mahnensmith, Zorzanello, Hsu & Williams, 2010; Su, Lu, Chen & Wang, 2009; Tawney, Tawney & Kovach, 2003; Woods, Port, Stannard, Blagg & Held, 1996). Though greater interest in self-management behavior is evident, its direct measurement has not been adequately developed making the assessment of patient outcomes and programs aimed at improving self-management behavior difficult to evaluate. A reliable and valid self-report instrument that measures the self-management amongst the adult hemodialysis population is needed.

In Canada, it is estimated that 2.6 million people have or are at risk of kidney disease (Kidney Foundation of Canada, 2012). The prevalence of ESRD has risen by 33% from 1998 to 2002 (Manns et al., 2007). Research demonstrates that the primary cause of kidney failure is attributable to vascular conditions specifically, diabetes and hypertension (Kidney Foundation of Canada, 2013). In 2010, 59% of adults diagnosed with kidney failure were treated with dialysis therapy (Kidney Foundation of Canada, 2012). The

Ontario Renal Network (2015) has reported that of the 10, 000 patients currently receiving dialysis therapies, 76% use facility-based services (in-center and satellite centers) and 6% home hemodialysis therapy. It is estimated that in-center/satellite hemodialysis therapy costs approximately $83, 000 per patient per year. The cost of home hemodialysis varies from $45, 000 to $58, 000 (Kidney Foundation of Canada, 2013). Given the rise in prevalence and health care costs associated with renal disease, the Ontario Renal Network has set strategic goals of improving self-management behaviors and the use of home hemodialysis (Visaya, 2010).

Self-management for adults receiving hemodialysis therapy is a complex issue that demands the development of considerable knowledge and skills (Novak, Costantini, Schneider & Beanlands, 2013). Some examples include the following: patients' i) ability to effectively communicate symptoms or other concerns to health care providers, ii) understanding of high potassium and phosphorous foods and how to augment the diet to avoid toxicity, iii) technical knowledge of the hemodialysis machine to support fluid removal preferences as well as other parameters that help reduce exacerbation of symptoms while receiving therapy, and iv) medication management including medications required because of the presence of other comorbid conditions (Curtin & Mapes, 2001; Curtin, Mapes, Schatell, & Burrows-Hudson, 2005; Curtin et al., 2008; Novak et al., 2013). These self-management activities place tremendous burden on the patient and demands a high level of psychological functioning and coping (Novak et al., 2013).

Adults receiving in-center/satellite and home hemodialysis therapy differ in their self-management skills and abilities. Research indicates that home hemodialysis recipients tend to be younger, have fewer comorbid conditions and perceive themselves as healthy individuals (MacGregor, 2011; Rygh, E., Arild, E., Johnsen, E., & Rumpsfeld, M, n.d.) These characteristics may support the uptake of home hemodialysis. Quantitative verification of this assumption is not possible because a reliable and valid instrument that measures self-management in the hemodialysis population was not found in the literature. However, adults who choose home hemodialysis must perform the therapy independently. This includes, having the hemodialysis machine installed in their home, setting up the machine, programming the prescription, connecting oneself to the machine, monitoring progress while on the machine, blood serum collection, and several other activities. The ability to successfully perform such skills suggests that adults on home hemodialysis have a high capacity for self-management. As such, it was anticipated that adults receiving in-center/satellite and home hemodialysis would differ in their self-management abilities and behaviors.

The persistent threats to life and many stressors encountered by those receiving dialysis may thwart self-management efforts and negatively impact cognitive and emotional processes. It has been suggested that people on dialysis attempt to control their situation by skipping treatments, requesting shorter treatment times, over consuming fluids, and failing to follow prescribed diet and medication regimes (Quinan, 2007). Additional analyses suggest that anxiety, depression and coping styles may be linked to self-management efforts (Sakraida & Robinson, 2012).

Anxiety and depression (collectively referred to as psychological distress) are common among adults with end stage renal disease and more prevalent as compared to healthy counterparts (Bossola et al., 2010; Chilcot, Wellsted, Da Silva-Gane & Farrington, 2008; Foster, Cohn, & McKegney, 1973; Feroze et al., 2012; Kimmel, 2002; Ormel et al., 2007; Ricardo et al, 2010; Wu et al., 2011). Anxiety has been associated with poor motivation and adherence (Claude, Hadjistavropoulos & Friesen, 2014; Luyster, Hughes & Gunstad, 2009; Pearce, Pereira, & Davis, 2013). Research suggests that in-center hemodialysis patients may experience increased anxiety possibly due to attending therapy sessions, receiving treatments from health care providers unfamiliar to the patient, and hearing the dialysis machine alarms (Feroze et al., 2012). Depression has been associated with higher rates of emergency room visits, hospital admissions (Abbas Tavallaii, Ebrahimnia, Shamspour, & Assari, 2009; Lopes et al., 2002), and fatigue, and suicidal ideation (Chen et al., 2010). Others have reported that adults receiving hemodialysis with diabetes have higher rates of anxiety and depression when compared to persons without diabetes. Those receiving in-center hemodialysis demonstrate higher levels of anxiety and more comorbidity as compared to those on home hemodialysis (Alavi, Aliakbarzadeh & Sharifi, 2009; Ginieri-Coccossis, Theofilou, Synodinou, Tomaras & Soldatos, 2008). This literature suggests that psychological states may affect self-management behaviors. Further adults on in-center/satellite hemodialysis versus home dialysis therapy may experience different levels of anxiety and depression, which can affect their ability to effectively manage their dialysis therapy.

Anxiety and depression may influence the coping strategies employed by adults afflicted with vascular disease on hemodialysis. Emotion-orientated, support seeking and avoidance coping has been linked to dependency on health care providers (Yeh & Chou, 2007) and poor attendance to medical appointments (Wolf & Mori, 2009). These methods of coping are higher among adults with comorbidities (Yeh, Huang & Chou, 2008). Interventions that incorporated coping and self-management training for adults with vascular disease reported improved coping and self-management practices and less anxiety (Kroese, Adriaanse, Vinkers, van de Schoot & Ridder, 2014; D'Eramo Melkus et al., 2010). Home hemodialysis patients have demonstrated more effective coping skills, supporting their ability to engage in a high level of independence and self-management (Lindqvist, Carlsson, & Sjoden, 1998; Nearhos, van Eps, & Connor, 2013).

When adults experience less effective coping and high levels of anxiety and depression, the severity of illness and symptom distress increases. This could interfere with their desire and ability to participate in research and complete a measure of self-management behavior. Therefore, a feasibility study to assess recruitment, consent and completion rates preceded any attempt to conduct a psychometric evaluation of a self-management tool. In addition, to explore the criterion validity of the tool a literature review was performed to examine the relationships between self-management, anxiety, depression and coping.

The Need for a Feasibility Study

A feasibility study was necessary to determine the viability of developing a psychometrically strong self-management instrument for the hemodialysis patient population. The multiplicity of patient issues combined with the complexity of operationalizing self-management could mean that the development of a reliable and valid self-report measure of self-management behavior is not possible (Streiner & Norman, 2008). Few self-management tools for adults with multiple comorbidities receiving hemodialysis therapy can be found in the literature. One instrument available in English measured adherence, a concept assumed to be associated with self-management. The tool was designed and tested with a sample of adults on hemodialysis and demonstrated weak reliability and validity (Kim, Evangelista, Phillips, Pavlish & Kopple, 2010). A comprehensive analysis of self-management instruments was fully described in Appendix A.

The Quantification of Self-Management

The operationalization of self-management is arduous owing to the diverse illness management requirements of adults on hemodialysis and multidimensional nature of the concept. Numerous definitions, theories and use of the term self-management can be found within the literature including those proposed by the World Health Organization (World Health Organization, 1983), Registered Nurses Association of Ontario (RNAO, 2010) and experts (Orem, 1985; Lorig & Holman, 2003). Not surprisingly, confusion regarding self-management has led to its interchangeable use with other terms such as self-care and association with related concepts. Researchers often use other constructs such as quality of life, illness perception, and health belief to explain variations in self-management interventions and health outcomes (Boyde, Turner, Thompson & Stewart, 2011; Chan, Wong & Chow, 2010; Chen, Tsai & Lee, 2009; Powers, Olsen, Oddone &

Bosworth, 2009; Su et al., 2009). These inconsistent definitions hinder the evaluation of self-management initiatives, as comparative analysis of research findings is not possible. Consistent measurement of self-management behavior would support standardized practice, a fundamental component of the Ontario Ministry of Health and Long-term Care patient based funding model (Ministry of Health and Long-term Care, 2014).

Study Objectives

The primary study objective was to conduct a feasibility study of the methods required to develop and explore the psychometric properties of the Vascular Disease Self-Management Instrument (VSMI) for adults receiving hemodialysis therapy. The feasibility outcomes included the recruitment, consent and completion rates and missing responses. These outcomes were selected based on seminal work (Thabane et al., 2010) and clinical expertise of the study investigator. Thabane et al (2010) provided comprehensive guidelines for feasibility studies and these standards integrated with clinical knowledge were applied to this thesis. The secondary study objective was to begin an exploratory analysis of the psychometric properties of the VSMI. This included examination of the reliability (internal consistency and test-retest), and construct validity using exploratory factor analysis and criterion-related validity of the VSMI. Criteria for psychometric analysis were based on recommendations from Streiner & Norman (2008). To support the criterion validity of the VSMI, other concepts including anxiety, depression and coping were examined.

Scope of the Thesis

- This thesis is a feasibility study. As such, the scope is limited to the specific purposes of a feasibility investigation
- To facilitate this process a purposeful sample of in-center/satellite and home hemodialysis patients were recruited for the study
- Study findings were described for the entire sample and by dialysis modality (in-center/satellite versus home hemodialysis) to provider greater depth of analysis for nephrology practitioners
- To effectively conduct preliminary psychometric evaluation of the VSMI, concurrent measurement of anxiety, depression and coping was proposed to examine criterion-related validity
- No attempts were made to generalize research findings. However, specific results by dialysis modality informs the nephrology clinical community
- Specifically, feasibility data highlighted methodological challenges and determined whether a psychometric evaluation of the self-report VSMI was a pragmatic and worthwhile research endeavor
- A reliable and valid self-report instrument would support the integration of self-management into routine clinical practices and facilitate the measurement of initiatives proposed by the Ontario Renal Network

CHAPTER 2

The Concept of Self-Management

A clear definition of self-management is necessary to support accurate measurement. A conceptual analysis conducted using the Walker and Avant (2011) method revealed that self-management and self-care are similar constructs with no discernable, significant differences (Costantini, 2013a; Hughes, 2010) (see Appendix B for complete conceptual analysis). As such, literature that examined self-management behaviors and self-care was analyzed. To avoid confusion with other health related phrases that contain the word care such as health-care or care services, this investigator recommends consistent use of the term self-management.

Self-management is a multidimensional concept comprised of five attributes including collaborative partnerships, self-advocacy, self-monitoring, illness-related activities and normalizing (Costantini, 2013a; Embrey, 2006; Hughes, 2010; Kawi, 2012; Rothenberger, 2011). Briefly, collaborative partnerships refers to working with health care providers to determine ways to best manage the illness; self-advocacy refers to asserting one's own preferences regarding treatment; self-monitoring is the cognitive appraisal of symptoms, illness-related activities are tasks that must be completed and normalizing is the adjustment of life around dialysis therapy (Costantini, 2013a; Costantini, Beanlands & Horsburgh, 2011). (A more detailed description of the attributes and corresponding definitions are presented in chapter three). Though these characteristics are numerous, the multiplicity is essential to address the management skills required given the complex and insidious nature of vascular diseases for adults receiving hemodialysis. Preliminary psychometric analysis would determine which attributes are specific to the reliable and valid quantitative measurement of self-management.

The Measurement of Self-Management

An extensive search of existing self-management instruments for adults with vascular disease was completed. The instruments were critically appraised using criteria based on Streiner & Norman (2008) (see Appendix A for the full analysis). The appraisal included assessment of reliability (internal consistency and test-retest), content validity, construct validity, predictive validity, discriminatory ability, and practical properties (number of items, time to complete tool and readability). Instruments designed to measure self-management or self-care were selected for analysis. The following instruments were identified and evaluated, the Self-Care of Heart Failure Index (Riegel, Carlson & Glaser, 2000; Riegel et al., 2004; Riegel, Lee, Dickson & Carlson, 2009), European Heart Failure Self-Care Behaviour Scale (Jaarsma, Arestedt, Martensson, Dracup & Stromberg, 2009; Jaarsma, Stromberg, Martensson & Dracup, 2003), Summary of Diabetes Self-Care Activities Scale (Toobert & Glasgow, 1994; Toobert, Hampson & Glasgow, 2000), Diabetes Self-Management Instrument (Lin, Anderson, Chang, Hagerty & Loveland-Cherry, 2008; Lin, 2005), and Chronic Kidney Disease Self-Efficacy Instrument (Lin et al., 2012). The participants involved in the evaluation of the above instruments were at risk for kidney disease due to their vascular conditions and had not started hemodialysis therapy. Nevertheless similarities amongst these instruments were evident providing support for instrument development. For example, collaboration with health care providers, self-monitoring, and illness-related activities were common attributes and subscales across these instruments. Any differences identified centered around symptoms distinct to heart failure and diabetes, necessitating the broadening of language to ensure applicability for those with multiple comorbidities receiving hemodialysis therapy.

Though the End Stage Renal Disease Adherence Questionnaire (ESRD-AD) (Kim et al., 2010) was not designed to measure self-management or self-care, it was assessed because the study sample included adults receiving hemodialysis therapy. The ESRD-AD combined different response formats that included Likert-scales, dichotomous (yes/no), and multiple-choice options making it difficult to evaluate the psychometric properties of the instrument. This instrument is not appropriate for use in research or clinical practice. The challenge to find instruments designed to measure self-management and tested with adults receiving hemodialysis demonstrates the need for tool development and its psychometric evaluation.

CHAPTER 3

Literature Review: The Search for Variables to Validate the VSMI

An extensive literature review was conducted to search for variables that would test the criterion validity of the VSMI. As such, research on self-management, psychological distress and coping was examined. To facilitate this analysis it was determined that broadening the search to include concepts similar to self-management would be necessary to facilitate greater depth of analysis. Comparable terms included self-care, self-efficacy and compliance or adherence. Self-care is not discernably different from self-management making it an ideal analogous term for literature extraction (Costantini, 2013a, Appendix B). Self-efficacy was defined as the belief in one's capacity to complete a course of action (Bandura, 1997). Compliance and adherence refers to the ability to perform activities as prescribed by health care providers (Berg, Evangelista, Carruthers, & Dunbar-Jacob, 2006). Self-efficacy, compliance and adherence are narrow concepts in comparison to self-management. However, the examination of other broader terms could introduce characteristics not common to self-management and potentially mislead conclusions obtained from the literature.

Literature Search Strategies

A literature search was conducted using OVID MEDLINE ® IN-PROCESS AND OTHER NON-INDEXED CITATIONS, OVID MEDLINE (R) DAILY AND OVID MEDLINE (R) 1946 TO PRESENT, EMBASE 1974 TO 2015 MAY 2015, OVID HEALTHSTAR 1966 TO APRIL 2015, PSYCINFO 1987 TO MAY WEEK 2 2015 AND CINAHL. The following terms facilitated literature extraction: "self-manage", "self-care", "self-efficacy", "compliance", "adherence", "anxiety", "coping", "psychological distress", "adaptation, psychological", "stress, psychological", "renal dialysis" and "dialysis". All terms with the exception of "self-manage" and "self-care" were exploded to support a comprehensive search strategy. This approach was developed in consultation with the McMaster University librarian to further ensure an extensive review.

Inclusion Criteria

The following inclusion criteria were employed:

1) Articles from peer-reviewed journals that contained the terms self-management, self-care, self-efficacy, compliance or adherence and psychological distress or anxiety and depression in the title or abstract and reported quantitative findings on the relationships amongst these concepts for adults receiving in-center/satellite hemodialysis or home hemodialysis therapy,
2) Publications that included self-management, self-care, self-efficacy, compliance or adherence and coping or stress in the title or abstract and examined the relationships between these concepts for adults receiving in-center/satellite hemodialysis or home hemodialysis therapy,
3) Observational study designs that investigated the associations between concepts to determine usefulness of psychological distress and coping as constructs for the test of criterion validity of the self-management instrument,
4) Adults 18 years of age or older,
5) Published in English

Exclusion Criteria

The exclusion criteria included the following:

1) Publications that involved renal transplantation, pre-dialysis, pediatrics, adolescents, caregivers, peritoneal dialysis therapy and vascular access as these are distinctly different populations,
2) Studies that examined other concepts such as quality of life or health beliefs,
3) Methodological research that included randomized controlled trials, interventions, and qualitative work

Search Strategy Results

The results of the search strategy are summarized in Table 1. Of the 540 publications located utilizing the databases, 277 were removed due to duplication. The inclusion/exclusion criteria were applied to remaining 263 articles. Nine publications met the inclusion and exclusion criteria. The other 254 articles were excluded for several reasons including; subjects were receiving other therapies (transplant, pre-dialysis, peritoneal dialysis, vascular access), incorrect age group (pediatrics, adolescents), caregiver burden, unrelated concepts (quality of life), employed varied methodologies (randomized controlled trials, interventions, qualitative), and failure to report on the relationships between self-management, self-care, self-efficacy, compliance/adherence and psychological distress or coping.

Quality Rating

The quality of the literature was assessed using the Strobe criteria (Vandenbrouke, et al., 2007) outlined in Table 2. Publications were evaluated based on the title, abstract, introduction, methods, participants, descriptive data, outcome data, main results, other analyses, and discussion. Each category of the Strobe consisted of additional subcategories to support a comprehensive evaluation totaling 30 criteria. To obtain a quality rating for the articles, each criterion was assigned a score of 1 if fully completed, 0.5 if partially completed and 0 if not reported. An example of a partially completed category may include a description of the research setting that did not disclose the relevant dates of data collection. The sum of the total score was divided by 30 and the percentage was reported as the quality rating.

Application of the Strobe criteria for the specific group of publications analyzed here revealed that the biases, sample size, missing data, sensitivity analysis and flow diagram were frequently omitted. As such, eliminating these 5 criteria and dividing the total score by 25 determined the adjusted quality rating. The unadjusted and adjusted scores for the Strobe criteria are reported as follows.

Literature Extraction Results

The results of the literature review are summarized in Table 3. The unadjusted and adjusted quality ratings ranged from 60% to 84% and 72% to 90%, respectively. All studies examined used observational designs. The major findings and analytic critique of the publications are described below.

Self-Management and Psychological Distress

Research on psychological distress (anxiety and depression) indicated important relationships that may affect self-management. The literature showed that higher levels of psychological distress were associated with poorer self-management (Li, Jiang & Lin, 2014) and self-care (Mollaoglu, 2006). Greater confidence in self-efficacy abilities was associated with lower anxiety, depression and symptom distress (Lev & Owen, 1998; Schneider, Friend, Whitaker, & Wadhwa, 1991). Adults with depression were more likely to report higher stress levels due to hemodialysis therapy (Scheider et al., 1991). These findings support the use of psychological distress as a measure to assess criterion validity.

Other studies examining psychological distress found that females were more likely to experience higher anxiety than males and older adults reported greater severity of depression than other age groups (Takaki et al., 2005). Increased anxiety was exacerbated by lack of social support diminishing self-care abilities (Mollaoglu, 2006). Those with depression were more likely to report higher stress levels due to hemodialysis therapy (Schneider et al., 1991). Greater psychological distress was evident amongst females, older adults and those with fewer social supports. This thesis collected data on demographic and social parameters. As such, these findings also support the measure of psychological distress in assessing criterion validity.

Self-Management and Coping

Several important relationships amongst psychological distress and coping were evident in the literature. Research indicated that higher levels of depression and anxiety were associated with emotion-oriented coping and lower self-efficacy (Takaki et al., 2003; Lev & Owen, 1998). O'Connor et al. (2008) reported that emotion-orientated coping was associated with greater variation of fluid compliance behaviors. However, task-orientated coping was more common amongst those with lower psychological distress and better compliance with fluid and diet restrictions (Christensen, Benotsch, Wiebe, & Lawton, 1995; Takaki et al., 2005). Examination of home hemodialysis users, a therapy that demands a high capacity for self-management, indicated that task-orientated coping was correlated with lower attrition from the program (Nearhos et al., 2013). This suggests that minimal psychological distress and task-orientated coping may enhance ones' ability to self-management when receiving hemodialysis therapy. Others including those with higher psychological distress and emotion-oriented coping are particularly vulnerable and require nursing interventions to enhance self-management outcomes. Further the relationships amongst self-management, psychological distress and coping suggest that the measurement of these variables would assist in the assessment of criterion validity of the VSMI.

Gaps in the literature

One article measured self-management and the instrument was not developed and tested in English. A reliable and valid English version of a self-management instrument for those receiving dialysis therapy is necessary for quantitative measurement of nursing outcomes and interventions reported in the English language. In addition, this would support greater consistency across English studies and negate use of narrow constructs such as self-efficacy and compliance. Four investigations analyzed in this literature review were conducted in other countries including China (1), Japan (2) and Turkey (1) (Li et al., 2014; Mollaoglu, 2006; Takaki et al., 2003; Takaki et al., 2005). Studies conducted in non-English speaking jurisdictions with varied cultural mores may limit applicability to North American participants. Studies with a larger number of task-orientated participants are necessary to verify whether there are any positive relationships between self-management and coping styles. Longitudinal studies and randomized controlled trials are required to determine if self-management interventions modify psychological distress and coping.

CHAPTER 4

Methodology

Study Design

This study assessed the feasibility of the study methods to develop and begin to explore the psychometric properties of the Vascular Disease Self-Management Instrument (VSMI). The research was conducted in three phases, the first feasibility of instrument development, the second feasibility of recruiting and testing from the adult hemodialysis population and third the beginning exploration of psychometric evaluation of the VSMI.

Primary Objectives – Feasibility

1) To determine the feasibility of the methods used to develop and begin to explore the psychometric properties of the VSMI. The methodological framework used for tool development was Streiner & Norman (2008). Instrument development consisted of item generation, item presentation, item selection and content validity. Feasibility of the methods used to begin to explore included recruitment, consent and completion rates and missing responses for the study. Feasibility outcomes and criteria were based on guidelines and recommendations found in the literature (Thabane et al., 2010) and clinical expertise of the investigator.

Secondary Objectives – Exploratory Psychometric Evaluation

2) To obtain preliminary evidence of the reliability (internal consistency and test-retest), and construct validity using exploratory factor analysis and criterion-related validity for the VSMI

3) To report data findings in three ways, for the entire study sample, and in-center/satellite and home hemodialysis participants

Phase One –Instrument Development of the VSMI

Item Generation, Item Presentation and Item Selection

The self-management instrument used in this study was a modified version of the Self-care for Adults on Dialysis tool (SCAD) designed to measure the self-care abilities and behaviors of persons over 18 years receiving dialysis therapy (Costantini, Beanlands & Horsburgh, 2011). For a full explanation of SCAD tool development and content validity testing refer to the following publication: Costantini, L., Beanlands, H., & Horsburgh, M. (2011). Development of the self-care for adults on dialysis tool (SCAD). *CANNT Journal, 21*(2), 38-43. A brief summary of this work is provided here. Item generation, presentation and selection for the SCAD tool was determined based on extensive literature review, analysis of the Lay Care-Giving for Adults Receiving Dialysis (LC-GAD) tool (Horsburgh, Laing, Beanlands, Meng, & Harwood, 2008) and collaboration with nephrology experts (Dr. Heather Beanlands & Dr. Beth Horsburgh). Content validity testing of the SCAD tool was completed with a panel of 13 nephrology experts that included advanced practice nephrology nurses, nurse practitioners and educators. The overall content validity index for the SCAD was 0.89. Expert feedback indicated that item and subscale revisions were needed (Costantini et al., 2011).

The revised SCAD tool has not undergone psychometric evaluation however, the instrument was utilized in a research study to evaluate a self-management education intervention (Trask, Marchuk, Rozon, Puyat & Costantini, 2015). Data were collected on the readability and clarity of items in the SCAD tool (Trask, 2013). Study findings indicated that significant modifications to several items were required. As such, a more in-depth examination of the self-care and self-management construct was conducted to ascertain greater clarity regarding the attributes, definitions and items that would best support tool development.

These study findings for the SCAD and the concept analysis summarized in chapter 2 where used to develop the five subscales pertinent to the operationalization of self-management. These included collaborative partnerships, self-monitoring, illness-related activities, self-advocacy and normalizing (Costantini, 2013; Embrey, 2006; Hughes, 2010; Kawi, 2012; Rothenberger, 2011). Subscale definitions are provided below.

Collaborative partnerships (CP).

A reciprocal relationship amongst patients and health care providers (physicians, registered nurses, pharmacists, dietitians) aimed at the mutual determination of plans of care that fit with the specific needs of the individual. This includes discussing disease information, treatment plans, prognosis, test results and illness management strategies (Costantini, 2013). The subscale consists of 10 items.

Self-advocacy (SA).

The patients' vigilance over their illness and treatment. Here patients independently seek information on the disease and/or various treatment options, ask for support from family/friends and assert their own preferences regarding treatment recommendations (Costantini, 2013). A total of 6 items comprise this subscale.

Self-monitoring (SM).

The patients' observation of bodily cues and appraisal of physiological signs related to the illness and/or treatment. This cognitive process precedes taking action and may include tracking physical (shortness of breath, weight gain) and emotional (anxiety, depression) symptoms (Costantini, 2013). The self-monitoring subscale contains 13 items.

Illness-related activities (IRA).

The performance of specific actions intended to ameliorate symptoms, complete prescribed treatment recommendations, and maintain health. Patients' may engage in activities such as, measuring their blood glucose, blood pressure, preparing meals or taking medications (Costantini, 2013). Twelve items were included in the subscale.

Normalizing (N).

The capacity to adjust one's preferred lifestyle around their illness and treatment. Patients may alter their medication regime or dialysis treatments to fit with their work schedule or family roles (child care, socializing, etc.) (Costantini, 2013). This subscale is comprised of 12 items.

As described in chapter 2, existing vascular disease self-management and self-care instruments were critically appraised to support development of the VSMI (Kim et al., 2010; Jaarsma et al., 2009; Jaarsma et al., 2003; Lin et al., 2008; Lin, 2005; Lin et al., 2012; Riegel et al., 2000; Riegel et al., 2004; Riegel et al., 2009; Toobert & Glasgow, 1994; Toobert et al., 2000). Similarities amongst these provided support of content analysis findings including VSMI subscales, definitions and items. For the VSMI, items were broadened to support relevance for adults with multiple vascular conditions receiving dialysis therapy.

Content Validity Testing of the VSMI

Content validity testing provides an indication of the extent to which an instrument and the items adequately represent the concept it was designed to measure (Waltz, Strickland & Lenz, 2005). Content validity index (CVI) is "the degree to which a scale has an appropriate sample of items to represent the construct of interest …" (Polit & Beck, 2006, p. 459). These terms and definitions were applied to the statistical analysis.

Study Setting

Nephrology experts from across Canada and many different settings were asked to take part in the study. Research settings included academia (universities) and clinical institutions (hemodialysis departments in hospitals and satellite centers).

Sample

A purposeful sample of 15 nephrology experts (professors, physicians, nurse practitioners and clinical specialists and educators) from across Canada were invited to evaluate the content validity of the instrument. A 50% response rate was anticipated resulting in a target sample of 7 experts, which was considered appropriate for content validity testing (Lynn, 1986; Polit & Beck, 2006).

Data collection and analysis

Nephrology experts were mailed a package that included the following: i) a letter of introduction, ii) instructions for the content validity assessment, iii) definitions of the self-management subscales, and iv) the VSMI with evaluation form (Appendix C).

Experts were asked to rate the relevance of each item on a 4-point Likert scale consisting of 1 ‘irrelevant’, 2 ‘somewhat relevant’, 3 ‘quite relevant’ and 4 ‘extremely relevant’. The content validity index (CVI) was calculated by totaling the proportion of all items that received a rating of 3 or 4. Items with a CVI of less than 80% were dropped from the instrument (Lynn, 1986; Polit & Beck, 2005; Waltz et al., 2005). As well, experts were asked to assess the fit of each item with the subscales and the overall completeness of the instrument in capturing self-management. The 55 items on the VSMI were randomized for the purposes of content validity testing. The data were analyzed to determine congruence between the investigator and nephrology experts. Based on these findings modifications to subscales, definitions and items were made.

A 7-point Likert scale was selected for item ranking (‘1 - never’, ‘2 – rarely’, ‘3 – occasionally’, ‘4 – sometimes’, ‘5 – frequently’, ‘6 – usually’, and ‘7 – always’). Research demonstrates that providing participants with more response categories improves the reliability, stability and discriminatory ability of instruments (Preston & Colman, 2000). The resultant final iteration of the VSMI was employed in phase two of this feasibility study.

Phase Two – Feasibility Outcomes

Based on Thabane et al. (2010), feasibility objectives specific to processes were assessed by examining recruitment, consent and completion rates. Comprehensive data were collected regarding the number of eligible participants, number and reasons for non-eligibility, rate of consent and rate of study completion. Recruitment rate refers to the number of participants that took part in the study divided by the total number of participants assessed for eligibility. Consent rate was defined as the percent of eligible participants that agreed to complete study questionnaires. Completion rate describes the proportion of eligible participants that completed the questionnaire package and the test-retest. Success criteria were determined based on the primary objectives of the study and the student investigator's clinical expertise. Based on the vulnerability of the hemodialysis population including illness severity and presence of multiple comorbidities it was anticipated that consent and completion rates greater than 50% were realistic targets. Results that fall below, met or exceed success criteria would inform the primary feasibility objectives of the study. Further no established feasibility benchmarks could be found in the literature. Other feasibility studies indicated that a wide variety of criteria are used tailored to the main objectives of the study (Cook et al., 2005; Pai et al., 2013, McMullin et al., 2007). As such, a similar approach was adopted for this study.

Resource issues included understanding study instruments and success criteria consisted of less than 5% missing data per questionnaire. This benchmark suggests that participants were agreeable to providing responses related to their self-management, psychological affect, and coping mechanisms. Table 1 summarizes the feasibility objectives and success criteria.

Phase Three – Preliminary Exploratory Psychometric Evaluation

Research Setting

The research setting was St. Joseph's Healthcare Hamilton – hemodialysis center in Hamilton, Ontario. The center comprises the largest regional kidney and urology program in the province and provides comprehensive services to patients with vascular diseases undergoing dialysis therapy. Program facilities are located across four sites - the Charlton (hospital), King (satellite/home hemodialysis program), Ohsweken (satellite), and Brantford Campuses (community hospital). The Charlton campus provides services to 250 patients, King campus 200 in-center and 180 independent dialysis (home hemodialysis and peritoneal dialysis) patients, Ohsweken 24 and Brantford 70 patients. Dialysis therapy consists of thrice-weekly treatments on Monday, Wednesday, Friday or Tuesday, Thursday, Saturday. Three different time slots are available including 0700, 1200, or 1800. Patients are given a specific campus, weekday and time to receive treatment.

Sample

A nonrandom sample of 133 participants were invited to take part in the study from the in-center/satellite and home hemodialysis programs.

Inclusion criteria

Individuals must have met the following criteria to participate in the study:

(a) Adults 18 years of age and older,
(b) Receiving hemodialysis therapy at an in-center/satellite facility or home hemodialysis and diagnosed with a vascular condition,
(c) Followed by a nephrologist at St. Joseph’s Healthcare Hospital Kidney and Urology program for greater than 3 months.

Exclusion criteria

Those experiencing the following were excluded from the study:

(a) Acute illness (admitted to hospital and/or experiencing adverse events during treatment (hypotension, cramps, vomiting, etc.),

(b) Cognitive impairment

(c) Unable to speak English.

Sample Size Rationale

To determine feasibility and conduct exploratory psychometric evaluation of the VSMI, a sample of 133 participants were recruited to support preliminary investigation of primary and secondary objectives (Private communication from Dr. L. Thabane: Dept. of Clinical Epidemiology & Biostatistics, April 8, 2014). Streiner & Norman (2008) recommend five participants per item to sufficiently power psychometric analyses. For the VSMI this would require a sample of 265 participants for a large-scale study. As such, a sample of 133 is half the size and should provide adequate preliminary data for feasibility analyzes (Private communication from Dr. L. Thabane: Dept. of Clinical Epidemiology & Biostatistics, April 8, 2014).

Recruitment

Potential study participants were recruited during their regularly scheduled dialysis treatment sessions. As patients arrived on the unit for treatment, registered nurses or renal assistants providing care informed potential participants that the student investigator would like to speak to them regarding the study. The student investigator approached interested participants to discuss and review the information sheet describing the project and the consent form (Appendix D). Consenting participants were provided with a signed copy of the consent form. Participants created their own unique identification number using their house number and last four digits of their telephone number. Names and identification numbers were maintained on a separate hard-copy paper.

Data Collection

The investigator made arrangements with participants to return during their dialysis session to complete study instruments. Questionnaires were completed independently whenever possible. For those requiring assistance (visually impaired), the student investigator read questions to participants and filled-in their responses. Participants were asked to complete the VSMI a second time during their next dialysis session (2 days later) to facilitate analysis of tool stability. Consenting participants were provided with a copy of the VSMI only during their next dialysis session.

Measures

The instruments used in the study are described below (See Appendix E). The K-10 and CISS: SSC were used to measure construct validity of the VSMI.

Sociodemographic Questionnaire.

Information regarding age, living arrangements, employment status, household income, education and medical history (comorbid conditions) was obtained from study participants.

Kessler Psychological Distress Scale (K10).

The Kessler Psychological Distress Scale (K10) is a 10-item self-report instrument used to measure level of anxiety and depression symptoms (Department of Health, 2002-2014). The scale consists of nonspecific psychological distress questions ranked using a

5-point Likert scale. The K10 can be completed in approximately 5 to 10 minutes. Possible scores range from 10 to 50 with higher scores indicating greater risk of anxiety or depression disorder (WHO Collaborating Center, 2000). Atlantis and Ball (2008) reported alpha coefficients of 0.83 to 0.85 demonstrating high internal consistency (Streiner & Norman, 2008).

The Coping Scale Inventory for Stressful Situations –Situation Specific (CISS: SSC).

The CISS: SSC is a 21-item tool that assesses three types of coping styles including task, emotion and avoidance-oriented coping. This instrument was based on the Coping Scale Inventory for Stressful Situations which has undergone extensive reliability and validity testing. The CISS-SSC employs a 5-point Likert rating scale ranging from 1 (not at all) to 5 (very much) and takes approximately 10 minutes to complete (Endler & Parker, 1994). The tool is appropriate for use with dialysis patients as they often experience stressful situations such as, needle cannulation, connection to the dialysis machine and progressive deterioration of their health. Further the determination of specific coping style is beneficial when attempting to measure and understand engagement in disease self-management. Coefficients for the CISS: SSC range from 0.71 to 0.85 suggesting the tool shows moderate to strong reliability (Endler & Parker, 1994; Streiner & Norman, 2008).

Data Analysis

The methods of analysis are summarized in Table 2.

Feasibility

Recruitment, consent and completion rates were described as frequencies. As well, the number and percent of missing responses for each questionnaire item was evaluated.

Descriptive Data

Descriptive statistics were used to summarize the sociodemographic variables of the sample. Descriptive data were presented in three ways which included findings for the entire sample, those receiving in-center/satellite therapy and home hemodialysis participants. Data analyses to substantiate the feasibility and provide preliminary psychometric analysis of the VSMI are outlined below.

Reliability (Internal Consistency and Test-Retest)

The internal consistency represents the homogeneity of scale items and was calculated using Cronbach's alpha coefficient (Waltz et al., 2005; Streiner & Norman, 2008). Test-retest reliability provides an indication of whether similar instrument scores would be obtained when a tool is administered under similar circumstances at different points in time. The test-retest was based on the Intraclass correlation coefficient (Streiner & Norman, 2008).

Construct Validity

Construct validity is "linking the attribute we are measuring to some other attribute by a hypothesis or construct" (Streiner & Norman, 2008, p. 10). The construct validity of the VSMI was established using exploratory factor analysis and criterion-related validity. Factors represent the subscales of the instrument and all factors are independent of one another. When applying exploratory factor analysis an evaluation is performed to determine the number of factors and which items correspond to each factor (Streiner & Norman, 2008; Waltz et al., 2005). Criterion-related validity "is the correlation of a scale with some other measure of the trait …" (Streiner & Norman, 2008, p. 254). For this study criterion-related validity was determined by administering another measure (K-10 and CISS: SSC) related to the VSMI and conducting hypothesis testing to establish the strength of the VSMI.

Exploratory Factor Analysis

Factor analysis was conducted with a covariance matrix and rotated factors to examine the data measured on a 7-point Likert scale (Norman & Streiner, 2008; Preston & Colman, 2000). The Bartlett Test of Sphericity and Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA) were used to ascertain which variables should be retained or eliminated from the instrument. Items with MSA values less than 0.70 and those with communalities below 0.60 were removed from the VSMI. As well, factor loading and factor rotation was performed. Factors that were statistically significant were retained and all others were discarded (Norman & Streiner, 2008).

Criterion-related validity

Criterion-related validity (a type of construct validity) was analyzed using several different validity tests as described below (Streiner & Norman, 2008).

Validity test 1.

Self-management and psychological distress as measured by the VSMI and K10 respectively, were examined by dividing participants into two groups – those with low K10 scores (10 to 15) and those with moderate (16-29) to high (30 to 50) K10 scores. It was hypothesized that participants with higher psychological distress would have lower self-management scores as studies demonstrate that poor emotional affect negatively influences health practices (Li, Jiang & Lin, 2014). Unpaired sample t-tests were calculated to determine whether self-management scores differed amongst the two groups of participants.

Validity test 2.

Coping as measured by the CISS: SSC was examined. Participants were divided into groups based on task, emotion and avoidance coping. It was anticipated that participants with task-oriented coping would demonstrate higher self-management scores. Those with emotion or avoidance coping would have lower self-management scores. This hypothesis was based on research that suggests coping impacts patients' well-being (Lazarus, 1993; Takaki et al., 2005). T-tests were used to analyze differences between coping style and self-management scores.

Missing data

Several strategies were employed to ensure completeness of data including checking all questionnaires at the time of data collection and asking participants for additional information. When necessary participants consulted with health care providers for assistance. For example, when unable to recall the year dialysis therapy was initiated. Despite these strategies missing data were evident. When sociodemographic variables were incomplete the number of missing responses was reported. For the K-10, participants were withdrawn from the study when responses were unanswered, as other forms of data management were not found. Endler & Parker (1999) recommend imputing a 3 for missing data on the CISS:SSC, as this is a neutral response based on the 5-point Likert scale. Similarly a response of 4 was imputed on the VSMI when required. When less than 5% of data was missing from questionnaires mean imputation was not performed given that statistical findings would not change significantly (Private communication from Dr. L. Thabane: Dept. of Clinical Epidemiology & Biostatistics, October 8, 2015).

Efforts to Minimize Bias

To reduce social desirability bias, eligible participants were assured that health care providers would not be privy to their responses (Streiner & Norman, 2008). The student investigator was not employed at any of the recruitment sites. Though participants were informed that the student investigator was a Registered Nurse she was not known by any of the participants. When participants required oral administration of questionnaires the investigator stopped speaking when health care providers were within hearing range to avoid unintended disclosure of responses.

The main purpose of the instruments was vaguely described to reduce deviation and social desirability bias (Streiner & Norman, 2008). For the K-10 terms such as ‘worry’ and ‘sadness’ were used in place of psychological distress. The CISS: SSC and VSMI were described verbally by the investigator as measures of ‘stress’ (Endler & Parker, 1999) and ‘dealing with the illness’, respectively (Streiner & Norman, 2008).

Ethics

This study was conducted in accordance with the Tri-Council Policy Statement, “Ethical Conduct for Research Involving Humans” (The Interagency Advisory Panel on

Research Ethics, 2007). Ethics approval for the study was obtained from the McMaster University Research and Ethics Board (Project number 14-415) and Brantford Hospital. All participants were provided with written informed consent for participation and renewed yearly as required. All data including demographics and item responses were kept strictly confidential. Information was stored in a locked cabinet and accessible to research staff only. Study participation was completely voluntary and subjects were advised that non-participation would not impact their treatment. Participants could withdraw at any time prior to data entry into the computer or refrain from answering any questions that caused discomfort. Should any distress occur, participants were directed to health care providers (doctor, nurse, social worker) that could provide support.

Data security was maintained by implementing several strategies. Identification numbers were determined by asking participants to create their own number using their house number and last four digits of their telephone number. The list of participant names and corresponding identification numbers were maintained on paper only and were not transcribed into the computer. Completed study documents and names/identification numbers were transported by the student investigator via her personal vehicle from St. Joseph’s Hospital to McMaster University for secure storage in a locked filing cabinet housed in Dr. Gina Browne’s office (supervisor). Data were entered into a password-protected computer using identification numbers only. The hard copies of study documents were kept until the completion of the PhD defense and will be destroyed confidentially using a shredder in 10 years. These processes will ensure protection of data and participant’s privacy.

CHAPTER 5

Results

Phase One –Instrument Development of the VSMI

Content Validity

The response rate for phase one of the study was low with 5 nephrology experts providing feedback. This is the minimum number required to determine content validity. As such, the content validity index was set high at 1.0 (Lynn, 1986).

Descriptive statistics of the sample of nephrology experts were not obtained to ensure anonymity. Data were collected from June 2014 to September 2014. This may have contributed to the low response rate as vacations or other activities are common during the summer months. One expert missed one page resulting in no responses for six items. Contacting the expert for clarification was not possible due to anonymity.

Of the 54 items included in the VSMI, 94% (n=51) were rated as relevant with a content validity index of 1.0 (Table 1). Three items including, items number 39 ("I ask for a copy of my blood laboratory results."), 47 ("I figure out ways to fit my dialysis therapy into my everyday life."), and 49 ("I think of my medical appointments (e.g. going to dialysis, medical appointments) as a chance to socialize with other people.") received a relevancy rating below 1.0. Item 39 was removed from the instrument. Items 47 and 49 were retained despite the low content validity index as similar statements were made to the student investigator during clinical interactions with hemodialysis patients in diverse treatment centers. Written feedback from one expert resulted in changes to items 19 and 22; specifically chest pain was added to the list of examples. Other recommendations such as foot pain, claudication and slow healing wounds are symptoms that not all patients experience potentially causing confusion when responding to questions. These examples were not added to the instrument. Changes based on the feedback from expert number five were not made, as the measurement of barriers to self-management was not the intended purpose of the instrument.

Phase Two –Feasibility Outcomes

Table 2 reflects the number of potential participants accessible from October 2014 to April 2015. Of the 418 patients attending dialysis at the 4 recruitment sites, 151 were ineligible for participation due to inability to speak or understand English (n = 45), received dialysis therapy for less than 3 months (n = 29), had cognitive impairment (n = 45) and experiencing acute illness requiring hospitalization (n = 32). The remaining 267 eligible patients were invited to take part in the study. A total of 131 declined participation with 127 refusals and 4 patients withdrew from the investigation (2 refused to complete the K-10 and 2 withdrew for other reasons). A total of 136 adults (123 patients undergoing in-center/satellite therapy and 13 utilizing home hemodialysis) consented to take part in the study.

Many of the feasibility criteria were met with success (Table 3). The minimum recruitment rate was achieved with 140 (52%) patients that initially agreed to participate in the study. The consent rate exceeded 50% with 136 patients (51%) maintaining their consent and responded to study questionnaires. The number of completers for the test-retest was less than anticipated (31.2%). Participants cited issues including feeling unwell, experiencing dialysis-related complications and fatigue as reasons for refusing to take-part in the re-test. Little missing data was evident for the study questionnaires.

Phase Three - Exploratory Psychometric Evaluation

Descriptive Statistics

The social, demographic and clinical characteristics of the total sample, those undergoing in-center/satellite hemodialysis and home hemodialysis are outlined in Table 4. Study participants overall were predominately male (61%) averaging 62 years of age. Participants were diagnosed with chronic kidney disease for a mean of 12 years and receiving dialysis therapy for a mean of 5.67 years. Here missing values were evident as participants were unable to recall the year initially diagnosed with kidney disease (missing values, n = 10) and when dialysis was commenced (missing value, n = 1). Participants consulted with health care providers to obtain information however chart thinning prohibited data extraction. Approximately half were highly educated (52.2% post-secondary education), married and/or common-law (53.7%), resided with their partners (52.9%), retired (48.5%) and earning $50 000 per annum or less (65.5%). Many participants had access to caregiver support (73.5%). About one-quarter of the sample reported the presence of another vascular condition (23.5%) and vascular conditions combined with other chronic illnesses (46.3%). Participants had on average 3 comorbid conditions. The majority of participants indicated that did not have a past history of anxiety or depression (77.2%).

The K-10 and CISS: SSC suggested that half the sample experienced moderate levels of psychological distress (50.0%) and primarily used avoidant-oriented coping

(50.7%) (Table 5). The average K-10 scores for the total sample was 18.80 (standard deviation = 6.67). The K-10 findings were similar for the in-center/satellite (mean = 18.97, standard deviation = 6.83) and home dialysis groups (mean = 17.23, standard deviation = 4.85). Comparison of coping disposition showed that a greater proportion of home hemodialysis participants used task-orientated coping (30.8%) as compared to in-center/satellite (13.0%). Regardless the avoidant style was higher for both groups.

Reliability

The Cronbach's alpha for each subscale demonstrated strong internal consistency (Table 6). However, elimination of low total item correlations (0.30 or lower) may further improve instrument reliability (Streiner & Norman, 2008) (see Table 7). For the Collaborative Partnerships subscale, correlations ranged from 0.477 to 0.686 therefore all items were retained. Two items were removed from the Self-Advocacy subscale. This included the following; 'I am comfortable asking others, for help with managing my illness' ($r = 0.208$) and 'I look for alternative therapy experts to help me manage my illness' ($r = 0.271$). The item 'I can recognize when I need help from health care providers' ($r = 0.156$) was eliminated from the Self-Monitoring subscale. The Illness-Related Activities subscale demonstrated the largest number of low item correlations for the total VSMI. The items 'When I experience body symptoms, I do things to help me feel better' ($r = 0.269$), 'I use alternative therapy experts to help me manage my illness' ($r = 0.271$), 'I take my medications as it has been prescribed for me' ($r = 0.296$), and 'I do things to take care of my dialysis access site' ($r = 0.315$) were discarded. As well, 'When I experience emotional symptoms, I do things to help me feel able to manage' ($r = 0.319$)

was removed from the instrument. When mental affect requires quantitative measurement other well-established tools are available. The item ‘I participate in my dialysis treatments’ ($r = 0.225$) was eliminated as the highly technological environment of the dialysis unit and computerized documentation has significantly limited opportunities for patient participation during treatment. For Normalcy two items were discarded, ‘I alter my medication schedule to fit with other areas of my life’ ($r = 0.181$) and ‘I think of my medical appointments as a chance to socialize with other people’ ($r = 0.344$). Content validity experts deemed the later item irrelevant and the poor correlation suggest removal was appropriate. For the remaining 42 items on the VSMI the Cronbach’s alpha was 0.945.

Test-Retest Reliability

The Intraclass correlation coefficient (ICC = 0.927, $p < 0.0001$) demonstrated strong tool stability further supported by the 95% confidence interval (0.893-0.955). This finding must be interpreted with caution due to the low completion rate (31.62%). Many participants initially consented to the retest and later refused reporting fatigue, feeling unwell, or experiencing dialysis-relating complications as reasons for their inability to complete the instrument on day two of the study.

Exploratory Factor Analysis

The variables and factor loadings were analyzed to determine consistency with the proposed instrument. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.794 suggesting sufficient sampling. The Bartlett Test of Sphericity ($X^2 = 2561.365$) was statistically significant ($p < 0.0001$) which may indicate the variables are related to each other (Norman & Streiner, 2008). Though the results are encouraging, Norman and Streiner (2008) recommend evaluating the mean sampling adequacy (MSA) of individual variables and eliminating those below 0.70 (Table 8). As such, the variables ‘I seek out written information about my illness and treatment’ (MSA = 0.598), ‘I figure out ways to make sure that my dialysis access site is protected (MSA = 0.648), and ‘When necessary, I figure out other ways to get the care I need’ (MSA = 0.657) were eliminated. Further variables with communalities less than 0.60 should be discarded from the matrix (Norman & Streiner, 2008). The following variables were eliminated ‘I try to be positive about my life in spite of my illness’ (0.488), ‘I can usually figure out the reasons for changes in my symptoms’ (0.562), ‘I think of my dialysis treatments as a way to stay healthy’ (0.489), ‘I follow a routine that fits with my preferred lifestyle (0.499), ‘I pay attention to blood laboratory results’ (0.544), and ‘I can figure out ways to manage my fatigue’ (0.543). Refer to Table 9 for a summary of eliminated items.

The remaining 33 variables were examined using the oblique Promax factor rotation as it was assumed that all factors were correlated (Norman & Streiner, 2008). Initially an eight-factor solution was evident however, two factors were discarded as the eigenvalues fell below 1.0. The final six-factor solution was extracted with eigenvalues of 30.726, 6.685, 6.378, 4.891, 4.372 and 3.740 and a total variance was 64.79% (Table 9).

The factors and significant factor loadings are outlined in Table 10. Interpretation was based on the following criterion; factor loadings less than 0.50 and factors with less than three variables were discarded (Norman & Streiner, 2008). For factor one, the variable ‘I pay attention to body signs and symptoms’ (0.396) and factor 4 ‘I find ways to protect my dialysis access site' (0.469) were eliminated. The variable 'I participate in making decisions about my treatment plan' loaded on factors two and three (0.441 and 0.468, respectively) and was discarded. Factors five and six were removed due to the low number of variables.

Factor 1 was named Collaborative Partnerships and consisted of 8 items with factor loadings ranging from 0.521 to 0.864. The factor captured activities involving working with health care providers to negotiate treatment plans and illness management.

Factor 2 was named Self-Monitoring, comprised of 5 items and factor loadings ranging from 0.634 to 0.691. It reflects cognitive aspects of managing end stage renal disease.

Factor 3 was named Self-Advocacy with 4 items and loadings ranging from 0.572 to 0.893. Here patients seek to individualize their illness management by obtaining information from peers and communicating needs to health care providers.

Factor 4 was named Normalcy composed of 4 items and factor loadings ranging from 0.595 to 0.809. This factor reflects efforts patients make to incorporate illness demands into their preferred lifestyle.

Criterion-related Validity

Criterion Validity Test 1.

Exploratory criterion validity was examined by determining whether participants with moderate to high psychological distress based on the K-10 scores would demonstrate lower self-management scores. Statistically significant differences were not evident (Table 11).

Criterion Validity Test 2.

It was hypothesized that those with task-oriented coping styles would demonstrate higher self-management scores as compared to those with emotion and/or avoidant coping. The statistically significant result suggested that participants utilizing task coping had higher self-management scores (Table 11). This finding provides preliminary evidence of criterion validity for the VSMI.

Chapter 6

Discussion

Lessons Learned from Feasibility Analysis

This study established feasibility and provides evidence that the methods used to develop and measure self-management behavior is possible for adults receiving hemodialysis therapy. The consent rate and little missing data suggested that the VSMI was acceptable to adults receiving hemodialysis therapy. Study participants were receptive to disclosing information on their abilities to collaborate with health care providers, advocate for their treatment preferences, monitor symptoms and health recommendations and maintaining normalcy.

The feasibility outcomes, specifically the completion rate, suggested that the severity of illness and number of comorbid conditions negatively impacted study participants' ability to take-part in the test-retest. Only 32% of the study participants completed the test-retest. Further participants often verbally reported feeling too ill or fatigued to complete the re-test for the VSMI. This presents a significant challenge for investigators, as it is difficult to predict or control the participants' personal experience of symptom distress and fatigue. Further exacerbation of symptoms may be owing to the high number of average comorbid conditions present in this study sample. An approach to ameliorate these issues is to conduct a multi-site study. This would provide access to a larger proportion of the adult hemodialysis population and potentially increase the number of study participants. A longer test-retest interval may be required to reduce burden on participants. Streiner & Norman (2008) recommended 2 to 14 day time lapse between test and retest periods. This study used a 2-day interval; a longer phase may be more appropriate to mitigate this issue. Alternatively, a longer period of time between data collection points risk differences in scores resulting from fluctuations in symptomology, development of acute illness or another compounding variable.

Other challenges included the low number of home hemodialysis participants. This group was particularly difficult to access due to their infrequent visits to health care centers. Though in-person recruitment and interviewing may improve quality of data (Streiner & Norman, 2008), it may not be realistic to obtain sufficient sample size using this approach necessitating mailed-out surveys for data collection.

Using a feasibility study design conserved valuable resources and findings indicated that the methodology could be successfully repeated in future larger scale studies (Thabane et al., 2010). Ensuring that the study design and evaluation of psychometric properties was a realistic research endeavor is important given the severity of illness and difficulties accessing home hemodialysis participants. This helps minimize overburdening seriously ill patients, such as those receiving dialysis therapy from consenting to studies that are poorly designed or do not include achievable objectives.

Lessons Learned from Preliminary Psychometric Evaluation

Preliminary psychometric evaluation suggests that the VSMI may provide a reliable and valid self-report instrument supporting quantification of self-management. The instrument is comprised of four subscales including collaborative partnerships, self-advocacy, self-monitoring and normalcy. The illness-related activities items had a low correlation with the total self-management instrument. Some items within this subscale elicited information regarding compliance to treatment recommendations. This suggests that the illness-related activities subscale was not correlated with the other subscales of the VSMI. Clinical parameters are available to support examination of compliance including serum potassium, interdialytic weight gain, shortening dialysis treatments, skipping treatments and many others. Though following treatment recommendations is important (National Kidney Foundation, 2015), a broader perspective of self-management is necessary to address the many issues adults on dialysis with multiple comorbidities encounter when striving to self-manage their illness.

Implications for Research

This study provides foundational knowledge from which to build future research. A full psychometric evaluation of the VSMI is required prior to its use in research and clinical practice setting. As part of the full evaluation, predictive validity testing may be performed. This may provide diagnostic information on self-management and facilitate development of large-scale initiatives to improve self-management. To reiterate future research should involve a multi-site study to compensate for the high level of illness severity evident for adults receiving hemodialysis therapy. As well, a longer test-retest interval period may be required to reduce symptom distress, fatigue and burden on study participants. Additional data collection (for example, symptom distress scale, level of fatigue) may be needed to determine whether these variables are impacting the measurement of self-management and if so to what extent.

The VSMI was designed as a self-report instrument. The instruments were distributed and completed during hemodialysis therapy sessions. Some study participants completed the instrument independently. Others required assistance due to visual impairments or their arm was restricted to prevent needle dislodgement during treatment. For these participants, the investigator administered the VSMI and verbal responses were recorded. Future research may include interviewer administration for all study participants to potentially improve recruitment and completion rates.

Implications for Practice

The VSMI gives health care providers with quantitative data regarding the level of self-management for the adult hemodialysis population. The subscales of VSMI may help health care providers to identify specific areas of self-management that require support and intervention. For example, an adult on hemodialysis scored poorly on the collaborative partnerships subscale. This may suggest that the person in not an appropriate candidate for home hemodialysis as extensive training and collaboration with health care providers is required. Intervention may be required prior to attempting a hemodialysis modality that requires a high level of self-management.

Half the sample showed moderate levels of psychological distress and half the study participants used avoidant-orientated coping. Assessment of anxiety, depression and coping are not commonly collected in the clinical practice setting. Though no statistically significant association between psychological distress and self-management was found in this study. The finding was inconsistent with other studies that reported a negative relationship between psychological distress and self-management (Li et al., 2014). Further task-orientated coping was more common amongst those on home hemodialysis suggesting that positive coping mechanisms support better self-management. More research is needed on representative samples to determine the relationships between anxiety, depression, coping and self-management to better inform clinical practice.

Limitations

Though the St Joseph's Healthcare Hamilton dialysis program serves up to 650 patients, the facilities were not operating at full capacity. This decline in operating capacity was attributable to the presence of patients' acute illnesses, deaths and other factors. As well, at the time of data collection there were ten other studies seeking similar patients which may have negatively contributed to patient recruitment, consent and burden (Private communication from G. Burns, St. Joseph's Healthcare, Hamilton, Transplant Clinics and Kidney Urinary Program Clinics, October 1, 2014). Together these issues may have decreased the number of patients agreeing to taking part or completing the study. Further the reasons for refusal to participate were not obtained due to ethical constrictions. The McMaster University Research and Ethics Board stated that any adult approached regarding a study should have the ability to refuse without being asked additional questions. Without this information it is difficult to ascertain all the factors negatively affecting recruitment and consent rates.

Home hemodialysis study participants were difficult to access. These potential participants were approached during visits to the King campus for issues requiring support from health care providers. This considerably limited the number of accessible participants and may have negatively impacted the small sample size for the home hemodialysis study participants. The peritoneal dialysis population was not included in the study. These patients attend brief follow-up appointments only at respective recruitment sites significantly limiting the opportunity for face-to-face contact. The only feasible method of recruitment and data collection with the peritoneal dialysis population was via mailing of study packages. The mixing of in-person data collection with mailed surveys may increase response variability (Streiner & Norman, 2008). Further there was no way to ensure that the retest of mailed questionnaires would be consistently completed on day two of the study. Consequently a large budget evaluation study would be required to support in-home face-to-face structured questionnaire administration and test-retest on day 2 on subsample.

Social desirability bias may have influenced responses to questionnaire items (Streiner & Norman, 2008). Data were collected during participants' dialysis sessions making it difficult to maintain privacy. Participants were in plain view of other patients and health care providers. As well, when participants required verbal administration others may have overheard responses. Considerable efforts were made to ensure confidentiality including refraining from speaking when others were within close proximity to the participant and strict concealment of data from health care providers. Regardless the presence of nurses within the unit during interviewing may have increased likelihood of providing positive responses. Further, nephrotoxicity was highest during dialysis therapy which may have adversely affected cognition (O'Connor et al., 2008). The extent to which nephrotoxicity may have influenced responses is unclear.

Interestingly, for in-center/satellite patients nursing, assessments are conducted prior to dialysis initiation and this information may be used to alter the dialysis prescription or alert the physician to a problem. Future research studies should consider whether interviewing participants on non-dialysis days is necessary.

Conclusions

The concept of self-management is not new, however its attributes and quantitative measurement are poorly understood (Costantini, 2013a Appendix B; Costantini, 2013b Appendix A). For those with vascular disease receiving hemodialysis therapy self-management is important to improve outcomes and reduce mortality and health care costs (Mahnensmith et al., 2010; Su et al., 2009; Tawney et al., 2003; Woods et al., 1996). Self-management endeavors are difficult for the vulnerable dialysis population as study findings suggested moderate to high levels of anxiety, depression, and emotion or avoidant-orientated coping (Takaki, et al., 2003; Takaki, et al., 2005). This psychological paradigm may considerably deter self-management efforts as distressed individuals often struggle to make positive, healthy choices (Christensen et al., 1995; O’Connor et al., 2008). This feasibility study suggests that adults receiving dialysis therapy require nursing interventions that support task-oriented coping strategies to improve self-management outcomes. Preliminary psychometric evaluation suggests that accurate quantification of self-management for adults on dialysis is achievable and larger studies should be performed to produce a final iteration of the VSMI for use in clinical practice and research.

References

Abbas, Tavallaii, S., Ebrahimnia, M., Shamspour, N., & Assari, S. (2009). Effect of depression on health care utilization in patients with end-stage renal disease treated with hemodialysis. *European Journal of Internal Medicine, 20*(4), 411-414. doi: 10.1016/j.ejim.2009.03.007

Alavi, N. M., Aliabarzadeh, Z., & Sharifi, K. (2009). Depression, anxiety, activities of daily living and quality of life scores in patients undergoing renal replacement therapies. *Transplantation Proceedings, 41,* 3693-3696.

Atlantis, E. & Ball, K. (2008). Association between weight perception and psychological distress. *International Journal of Obesity, 32*, 715-721.

Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: Freeman Press.

Berg, J., Evangelista, LS., Carruthers, D., & Dunbar-Jacob, J.M. (2006). Compliance. In I.M. Lubkin & P.D. Larsen (Eds.), Chronic illness: Impact and interventions (pp. 221-252). Sudbury, MA: Jones and Bartlett Publishers.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of American Medical Association, 288*(19), 2169-2175.

Bossola, M., Ciciarelli, C., Conte, G. L., Vulpio, C., Luciani, G., & Tazza, L. (2010). Correlates of symptoms of depression and anxiety in chronic hemodialysis patients. *General Hospital Psychiatry, 32,* 125-131.

Boyde, M., Turner, C., Thompson, D. R., & Stewart, S. (2011). Educational interventions for patients with heart failure: A systematic review of randomized controlled trials. *Journal of Cardiovascular Nursing, 26*(4), E27-35.

Chan, M. F., Wong, F. K. Y., & Chow, S. K. Y. (2010). Investigating the health profile of patients with end-stage renal failure receiving peritoneal dialysis: A cluster analysis. *Journal of Clinical Nursing, 19*(5-6), 649-657. doi: http://dx.doi.org/10.1111/j.1365- 2702.2009.03103.x

Chen, C. K., Tsai, Y., Hsu, H., Wu. I., Sun, C., Chou, C. …Wang, L. (2010). Depression and suicide risk in hemodialysis patient with chronic renal failure. *Psychosomatics, 51*(6), 528-528:e6.

Chen, S. L., Tsai, J. C., & Lee, W. L. (2009). The impact of illness perception on adherence to therapeutic regimens of patients with hypertension in Taiwan. *Journal of Clinical Nursing, 18*(15), 2234-2244.

Chilcot, J., Wellsted, D., Da Silva-Gane, M., & Farrington, K. (2008). Depression on dialysis. *Nephron Clinical Practice, 108*(4), c256-264. doi: 10.1159/000124749.

Christensen, A. J., Benotsch, E. G., Wiebe, J. S. & Lawton, W. J. (1995). Coping with treatment-related stress: Effects on patient adherence in hemodialysis. *Journal of Consulting and Clinical Psychology, 63*(3), 454-459.

Claude, J. A., Hadjistavropoulos, H. D., & Friesen, L. (2014). Exploration of health anxiety among individuals with diabetes: Prevalence and implications. *Journal of Health Psychology, 19*(2), 312-322.

Cook, D. J., Rocker, G., Meade, M., Guyatt, G., Geerts, W., Anderson, D., … Growther,

M. (2005). Prophylaxis of thromboembolism in critical care (Project) trial: A pilot study. *Journal of Critical Care, 20*, 364-372.

Costantini, L. (2013)a. *Conceptualization of self-management for adults with chronic kidney disease*. Unpublished comprehensive exam paper, McMaster University.

Costantini, L. (2013)b. *Measurement of self-management for adults with vascular diseases: A critical analysis*. Unpublished comprehensive exam paper, McMaster University.

Costantini, L., Beanlands, H., & Horsburgh, M. (2011). Development of the self-care for adults on dialysis tool (SCAD). *CANNT Journal*, *21*(2), 38-43.

Curtin, R. B., & Mapes, D. L. (2001). Health care management strategies of long-term dialysis survivors. *Nephrology Nursing Journal, 28*, 385-392.

Curtin, R. B., Mapes, D., Schatell, D., & Burrows-Hudson, S. (2005). Self-management in patients with end stage renal disease: Exploring domains and dimensions. *Nephrology Nursing Journal, 32,* 389-395.

Curtin, R. B., Walters, B. A., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Advances in Chronic Kidney Disease, 15*(2), 191-205. doi: http://dx.doi.org/10.1053/j.ackd.2008.01.006

Department of Health (2002-2014). *Population research and outcomes studies. Brief reports: The Kessler Psychological Distress Scale (K10).* Government of South Australia. Retrieved from http://health.adelaide.edu.au/pros/docs/reports/br200214_k10.pdf.

D'Eramo Melkus G, Chyun D, Vorderstrasse A, Newlin K, Jefferson V, & Langerman S. (2010). The effect of a diabetes education, coping skills training, and care intervention on physiological and psychosocial outcomes in black women with type 2 diabetes. *Biological Research for Nursing, 21*(1), 7-19. doi: 10.1177/1099800410369825

Embrey, N. (2006). A concept analysis of self-management in long-term conditions. *British Journal of Neuroscience Nursing, 2*(10), 507-513.

Endler, N. S. & Parker, J. D. A. (1994). Assessment of multidimensional coping: Task, emotion, and avoidance strategies. *Psychological Assessment, 6*(1), 50-60.

Feroze, U., Martin, D., Kalantar-Zadeh, K., Kim, J. C., Reina-Patton, A., & Kopple, J. D. (2012). Anxiety and depression in maintenance dialysis patients: Preliminary data of a cross-sectional study and brief literature review. *Journal of Renal Nutrition, 22*(1), 207-210.

Foster, F. G., Cohn, G. L., & McKegney, F. P. (1973). Psychobiologic factors and individual survival on chronic renal hemodialysis. A two year follow-up. *Psychosomatic Medicine, 35*(1), 64-82.

Ginieri-Coccossis, M., Theofilou, P., Synodinou, C., Tomaras, V. & Soldatos, C. (2008). Quality of life, mental health and health beliefs in haemodialysis and peritoneal dialysis patients: Investigating differences in early and later years of current treatment. *BMC Nephrology, 9*, 14. doi: 10.1186/1471-2369-9-14

Horsburgh, M. E., Laing, G., Beanlands, H., Meng, A. X., & Harwood, L. (2008). A new measure of “lay” care-giver activities. *Kidney International, 74*, 230-236.

Hughes, L. (2010). *Chronic disease self-management: An evolutionary concept analysis*. Retrieved from http://dspace.library.uvic.ca:8080/bitstream/handle/1828/4057/ Hughes_Lori _MN_ 2010.pdf?sequence=1.

Jaarsma, T., Arestedt, K. F., Martensson, J., Dracup, K., & Stromberg, A. (2009). The European Heart Failure Self-care Behavior scale revised into a nine-item scale (EHFScB-9): A reliable and valid international instrument. *European Journal of Heart Failure, 11*, 99-105.

Jaarsma, T., Stromberg, A., Martensson, J., & Dracup, K. (2003). Development and testing of the European Heart Failure Self-Care Behaviour Scale. *The European Journal of Heart Failure, 5,* 363-370.

Kawi, J. (2012). Self-management support in chronic illness care: A concept analysis. *Research and Theory for Nursing Practice: An International Journal, 26*(2), 108-125.

Kim, Y., Evangelista, L. S., Phillips, L. R., Pavlish, C., & Kopple, J. D. (2010). The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ): Testing the psychometric properties in patients receiving in-center hemodialysis. *Nephrology Nursing Journal*, *37*(4), 377-393.

Kimmel, P. L. (2002). Depression in patients with chronic renal disease: What we know and what we need to know. *Journal of Psychosomatic Research, 53,* 951-956.

Kidney Foundation of Canada (2012). *The foundation of kidney care, facing the facts: Includes highlights from the Canadian Organ Replacement Register*. Retrieved from http://www.kidney.ca/document.doc?id=1376

Kidney Foundation of Canada (2013). *The foundation of kidney care, facing the facts: Includes highlights from the Canadian Organ Replacement Register*. Retrieved from http://www.kidney.ca/document.doc?id=4083

Kroese, F. M., Adriaanse, M. A., Vinkers, C. D. W., van de Schoot, R., & de Ridder, T. D. (2014). The effectiveness of a proactive coping intervention targeting self-management in diabetes patients. *Psychology & Health, 29*(1), 110-125. doi.org//10.1080/ 08870446.2013.841911.

Lev, E. L. & Owen, S. V. (1998). A prospective study of adjustment to hemodialysis. *ANNA Journal, 25*(5), 495-504.

Li, H., Jiang, Y., & Lin, C. (2014). Factors associated with self-management by people undergoing hemodialysis: A descriptive study. *International Journal of Nursing Studies, 51*, 208-216.

Lin, C. C. (2005). *Development and testing of the diabetes self-management instrument*. Unpublished doctoral dissertation, The University of Michigan.

Lin, C. C., Anderson, R. M., Chang, C. S., Hagerty, B. M., & Loveland-Cherry, C. J. (2008). Development and testing of the Diabetes Self-Management Instrument: A confirmatory analysis. *Research in Nursing & Health, 31*, 370-380.

Lin, C. C., Wu, C. C., Anderson, R. M., Chang, C. S., Chang, S. C., Hwang, S. J., & Chen, H. C. (2012). The chronic kidney disease self-efficacy (CKD-SE) instrument: Development and psychometric evaluation. *Nephrology Dialysis Transplantation, 27*, 3828-3834.

Lindqvist, R., Carlsson, M., & Sjoden, P. (1998). Coping strategies and quality of life among patients on hemodialysis and continuous ambulatory peritoneal dialysis. *Scandinavian Journal of Caring Sciences, 12*, 223-230.

Lopes, A. A., Bragg, J., Young, E., Goodkin, D., Mapes, D., Combe, C., Piera, L., Held, L., Gillespie, B., & Port, F. K. (2002). Depression as a predictor of morality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International, 62*(1), 199-207.

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definitions, outcomes, and mechanisms. *Annals in Behavioral Medicine, 26*(1), 1-7.

Luyster, F. S., Hughes, J. W. & Gunstad, J. (2009). Depression and anxiety symptoms are associated with reduced dietary adherence in heart failure patients treated with an implantable cardioverter defibrillator. *Journal of Cardiovascular Nursing, 24*(1), 10-17.

Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research, 35*(6), 382-386.

MacGregor, M. S. (2011). Outcomes on home hemodialysis: Registry challenges. *Nephrology Dialysis Transplantation Plus, 4*(Suppl 3), iii32-iii35. doi: 10.1093/ndtplus/sfr126.

Mahnensmith, R. L., Zorzanello, M., Hsu, Y., & Williams, M. E. (2010). A quality improvement model for optimizing care of the diabetic end-stage renal disease patient. *Seminars in Dialysis, 23*(2), 206-213. doi: 10.1111/j.1525-139X.2010.00717.x.

Manns, B. J., Mendelssohn, D. C., & Taub, K. J. (2007). The economics of end-stage renal disease care in Canada: Incentives and impact on delivery of care. *International Journal of Health Care Finance Economy, 7*(2-3), 149-169.

McMullin, J., Brozek, J., McDonald, E., Clarke, F., Jaeschke, R., Heels-Ansdell, D., … Cook, D. (2007). Lowering of glucose in critical care: A randomized pilot trial. *Journal of Critical Care, 22*(2), 112-118. doi: http://dx.doi.org/10.1016/j.jcrc.2006.08.002

Ministry of Health and Long-term Care (2014). *Patient-based funding overview*. Retrieved from http://www.health.gov.on.ca/en/pro/programs/ecfa/docs/ecfa_funding pres.pdf.

Mollaoglu, M. (2006). Perceived social support, anxiety, and self-care among patients receiving hemodialysis. *Dialysis & Transplantation, 35*(3), 144-155, 183.

National Kidney Foundation. (2015). *Kidney Disease Outcomes Initiatives Clinical practice guidelines for hemodialysis adequacy: 2015 update*. Retrieved from http://www.ajkd.org/article/S0272-6386(15)01019-7/pdf

Nearhos, J., van Eps, C., & Connor, J. (2013). Psychological factors associated with successful outcomes in home haemodialysis. *Nephrology, 18*, 505-509.

Norman, G. R. & Streiner, D. L. (2008). *Biostatistics: The bare essentials (3rd Ed.).* Shelton, Connecticut: People’s Medical Publishing House.

Novak, M., Costantini, L., Schneider, S., & Beanlands, H. (2013). Approaches to self-management in chronic illness. *Seminars in Dialysis, 26*(2), 188-194. doi: 10.1111/sdi12080.

O'Connor, S. M., Jardine, A. G., & Millar, K. (2008). The prediction of self-care behaviors in end-stage renal disease patients using Leventhal's Self-Regulatory Model. *Journal of Psychosomatic Research, 65*, 191-200. doi: 10.1016/ j.jpsychores.2008.02.008.

Ontario Renal Network (2015). Prevalence: Proportion of prevalent dialysis patients by treatment type, Ontario, as of September 30, 2014. Retrieved from http://www. renalnetwork.on.ca/ontario_renal_plan/our_progress_so_far/#.VrO_Pkv7WFI

Orem, D. E. (1985). A concept of self-care for the rehabilitation client. *Rehabilitation Nursing Journal, 10*(3), 33-36.

Ormel, J., Von Korff, M., Burger, H., Scott, K., Demyttenaere, K., Huang, Y., …Kessler, R. (2007). Mental disorders among persons with heart disease – results from World Mental Health surveys. *General Hospital Psychiatry, 29*, 325-334.

Pearce, M. J., Pereira, K., & Davis, E. (2013). The psychological impact of diabetes: A practical guide for the nurse practitioner. *Journal of the American Association of Nurse Practitioners, 25,* 578-583.

Pai, M., Lloyd, N. S., Cheng, J., Thabane, L., Spencer, F. A., Cook, D. J., … Douketis, J. D. (2013). Strategies to enhance venous thromboprophylaxis in hospitalized medical patients (SENTRY): A pilot cluster randomized trial. *Implementation Science, 2*(8), 1. doi: 10.1186/1748-5908-8-1.

Polit, D. F. & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health, 29*, 489-497.

Powers, B. J., Olsen, M. K., Oddone, E. Z., & Bosworth, H. B. (2009). The effect of a hypertension self-management intervention on diabetes and cholesterol control. *American Journal of Medicine, 122*(7), 639-646. doi: http://doi.org/10.1016/ j.amjmed.2008l12.022

Preston, C. C. & Colman, A. M. (2000). Optimal number of response categories in rating scales: Reliability, validity, discriminating power, and respondent preferences. *Acta Psychologica, 104*, 1-15.

Quinan, P. (2007). Control and coping for individuals with end stage renal disease on hemodialysis: A position paper. *The CANNT Journal, 17*(3), 77-84.

Registered Nurses Association of Ontario (2010). *Best practice guideline - Strategies to support self-management in chronic conditions: Collaboration with clients*. Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_ Chronic_Conditions_-_Collaboration_with_Clients.pdf.

Ricardo, A. C., Fischer, M. J., Peck, A., Turyk, M., & Lash, J. P. (2010). Depressive symptoms and chronic kidney disease: Results from the National Health and Nutrition Examination Survey (NHANES) 2005-2006. *International Urology and Nephrology, 42(*4), 1063-1068. doi:10.1007/s11255-010-9833-5

Riegel, B., Carlson, B., & Glaser, D. (2000). Development and testing of a clinical tool measuring self-management of heart failure. *Heart & Lung, 29*(1), 4-12.

Riegel, B., Carlson, B., Moser, D. K., Sebern, M., Hicks, F. D., & Roland, V. (2004). Psychometric testing of the self-care of heart failure index. *Journal of Cardiac Failure, 10*(4), 350-360.

Riegel, B., Lee, C. S., Dickson, V. V., & Carlson, B. (2009). An update on the self-care of heart failure index. *Journal of Cardiovascular Nursing, 24*(6), 485-497.

Rothenberger, C. D. (2011). Chronic illness self-management in prediabetes: A concept analysis. *Journal of Nursing and Healthcare of Chronic Illness: An International Journal, 3*, 77-86. doi:10.1111/j.1752-9824.2011.01092.x

Rygh, E., Arild, E., Johnsen, E., & Rumpsfeld, M. (n.d.). Choosing to live with home dialysis – patients' experiences and potential for telemedicine support: A qualitative study. Retrieved from http://www.biomedcentral.com/imedia/1094023406560745_manuscript.pdf

Sakraida, T. J. & Robinson, M. V. (2012). Mental health and relational self-management experiences of patients with type 2 diabetes and stage 3 chronic kidney disease. *Issues in Mental Health Nursing, 33*, 786-796. doi: 10.3109/01612840.2012.713446

Schneider, M. S., Friend, R., Whitaker, P., & Wadhwa, N. K. (1991). Fluid noncompliance and symptomatology in end-stage renal disease: Cognitive and emotional variables. *Health Psychology, 10*(3), 209-215.

Streiner, D. L., & Norman, G. R. (2008). *Health Measurement Scales: A Practical Guide to their Development and Use*. New York, NY: Oxford University Press.

Su, C., Lu, X., Chen, W., & Wang, T. (2009). Promoting self-management improves the health status of patients having peritoneal dialysis. *Journal of Advanced Nursing, 65*(7), 1381-1389. doi: http://dx.doi.org/10.1111/j.1365-2648.2009.04993.x

Takaki, J., Nishi, T., Shimoyama, H., Inada, T., Matsuyama, N., Kumano, H., & Kuboki,

T. (2003). Interactions among a stressor, self-efficacy, coping with stress, depression, and anxiety in maintenance hemodialysis patients. *Behavioral Medicine, 29*(3), 107-112.

Takaki, J., Nishi, T., Shimoyama, H., Inada, T., Matsuyama, N., Kumano, H., & Kuboki, T. (2005). Possible interactive effects of demographic factors and stress coping mechanisms on depression and anxiety in maintenance hemodialysis patients. *Journal of Psychosomatic Research, 58*, 217-223. doi: 10.1016/ j.jpsychores. 2004.09.003.

Tawney, K. W., Tawney, P. J. W., & Kovach, J. (2003). Disablement and rehabilitation in end-stage renal disease. *Seminars in Dialysis, 16*(6), 447-452.

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, P. L., Robson, R., Thabane, M., Giangregorio, L., & Goldsmith, H. G. (2010). A tutorial on pilot studies: The what, why and how. BMC Medical Research Methodology, 10(1). doi: 10.1186/1471-2288-10-1.

The Interagency Advisory Panel on Research Ethics. (2007). *Harmonisation of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS) and ICH-Good Clinical Practice: Conflict or Clarification?* Retrieved from http://www.pre.ethics.gc.ca/policy-politique/initiatives/docs/FINAL_TCPS-GCP_Harmonization_Nov_2007_-_EN.pdf

Toobert, D. J., & Glasgow, R. E. (1994). *Assessing diabetes self-management: Summary of Diabetes Self-Care Activities Questionnaire*. In C. Bradley (Ed.), Handbook of psychology and diabetes (pp. 351-375). Langhorne, PA: Harwood Academic

Publishers.

Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The summary of diabetes self-care activities measure. *Diabetes Care*, *23*, 943-950.

Trask, M. (2013). *The SCAD Feedback*. Unpublished data, Providence Health, British Columbia.

Trask, M., Marchuk, S., Rozon, C., Puyat, J. H. & Costantini, L. (2015). The evaluation of an orientation program on self-care abilities for hemodialysis patients. Manuscript submitted for publication.

Vandenbroucke, J. P., von Elm, E., Altman, D. G., Gotzsche, P. C., Mulrow, C. D., Pocock, S. J., Poole, C., Schlesselman, J. J., & Egger, M. for the Strobe Initiative. (2007). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): Explanation and Elaboration. *Epidemiology*, *18*(6), 805-835.

Visaya, M. A. (2010). Hemodialysis patients' perceptions of home hemodialysis and self-care. *CANNT Journal*, *20*(2), 23-28.

Walker, L. O. & Avant, K. C. (2011). *Strategies for Theory Construction in Nursing*. Upper Saddle River, NJ: Prentice Hall.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2005). *Measurement in Nursing and Health Research*. New York, NY: Springer Publishing Company.

WHO Collaborating Center (2000). *K10 Symptom Scale*. Clinical Research Unit for Anxiety and Depression. School of Psychiatry, University of New South Wales. Retrieved from: http://www.crufad.unsw.edu.au/K10/k10info.htm.

Wolf, E. J. & Mori, D. L. (2009). Avoidant coping as a predictor of mortality in Veterans with end-stage renal disease. *Health Psychology, 28*(3), 330-337.

Woods, J. D., Port, F. K., Stannard, D., Blagg, C. R., & Held, P. J. (1996). Comparison of mortality with home hemodialysis and center hemodialysis: A national study. *Kidney International, 49*(5), 1464-1470.

World Health Organization (1983). *Health education in self-care: Possibilities and limitations*. Retrieved from http://apps.who.int/iris/bitstream/10665/70092/1/HED _84.1.pdf.

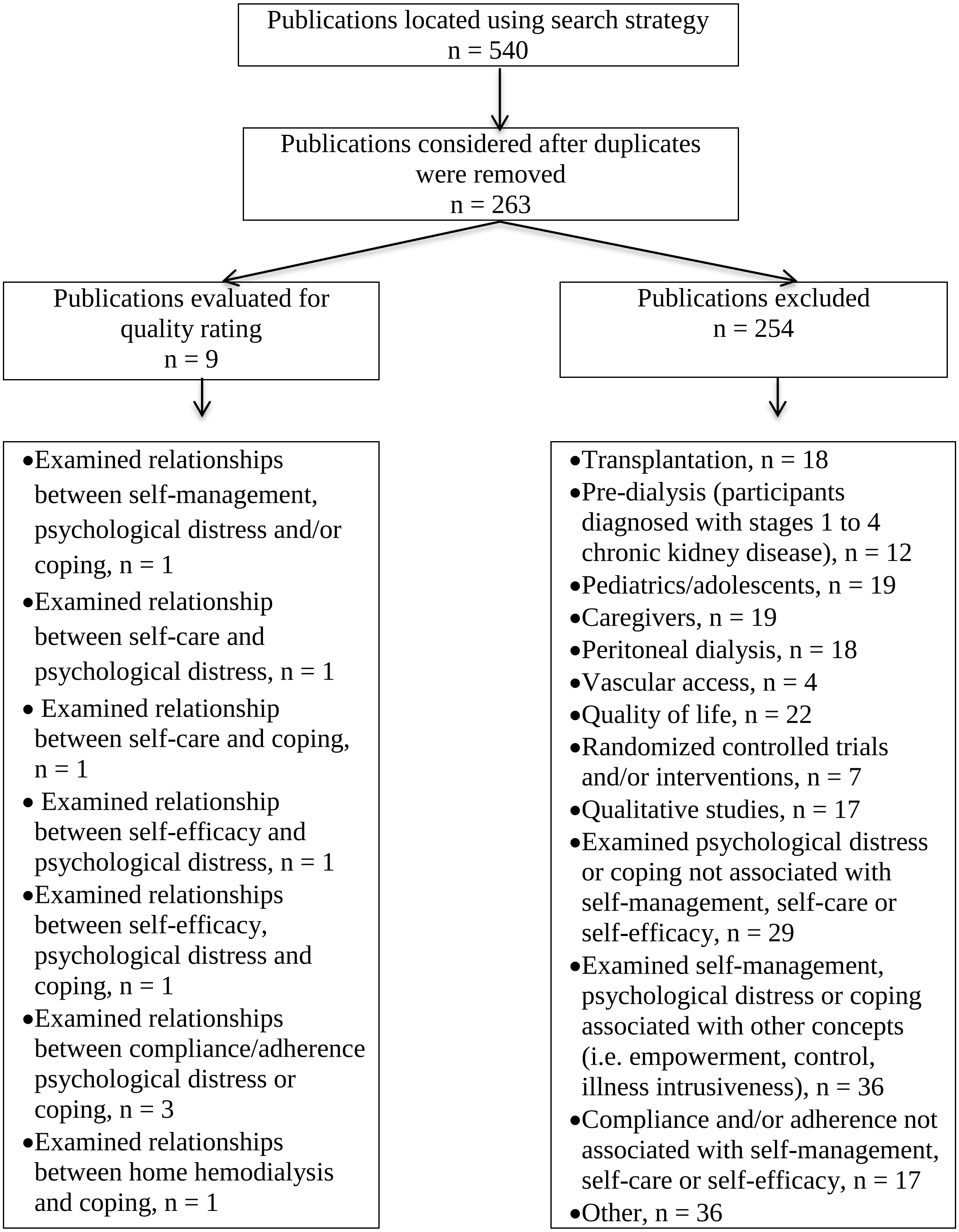
Wu, S. V. Huang, Y., Liang, S., Wang, T., Lee, M., Tung, H. (2011). Relationships among depression, anxiety, self-care behavior and diabetes education difficulties in patients with type-2 diabetes: A cross-sectional questionnaire survey. *International Journal of Nursing Studies*, *48*, 1376-1383. doi: 10.1016/j.ijnurstu.2011.04.008

Yeh, S. J., & Chou, H. (2007). Coping strategies and stressors in patients with hemodialysis. *Psychosomatic Medicine, 69*, 182-190.

Yeh, S. J., Huang, C. H., & Chou, H. (2008). Relationships among coping, comorbidity and stress in patients having haemodialysis. Journal of Advanced Nursing, 63(2), 166-174. doi: 10.1111/j.1365-2648.2008.04659.x

Chapter 3

Table 1 Summary of literature search results



Publications located using search strategy
n = 540

Publications considered after duplicates were removed
n = 263

Publications evaluated for quality rating
n = 9

- Examined relationships between self-management, psychological distress and/or coping, n = 1
- Examined relationship between self-care and psychological distress, n = 1
- Examined relationship between self-care and coping, n = 1
- Examined relationship between self-efficacy and psychological distress, n = 1
- Examined relationships between self-efficacy, psychological distress and coping, n = 1
- Examined relationships between compliance/adherence psychological distress or coping, n = 3
- Examined relationships between home hemodialysis and coping, n = 1

Publications excluded
n = 254

- Transplantation, n = 18
- Pre-dialysis (participants diagnosed with stages 1 to 4 chronic kidney disease), n = 12
- Pediatrics/adolescents, n = 19
- Caregivers, n = 19
- Peritoneal dialysis, n = 18
- Vascular access, n = 4
- Quality of life, n = 22
- Randomized controlled trials and/or interventions, n = 7
- Qualitative studies, n = 17
- Examined psychological distress or coping not associated with self-management, self-care or self-efficacy, n = 29
- Examined self-management, psychological distress or coping associated with other concepts (i.e. empowerment, control, illness intrusiveness), n = 36
- Compliance and/or adherence not associated with self-management, self-care or self-efficacy, n = 17
- Other, n = 36

Table 2 Strobe Criteria (Vandenbrouke, et al., 2007)

Strobe Checklist	**Score**	**Comments/ Details**
Title and abstract		
Indicate the study's design with a commonly used term in title **OR** abstract		
Provide in the abstract an informative and balanced summary of what was done and what was found		
Introduction		
Explain the scientific background and rationale for the investigation being reported		
State specific objectives, including any pre-specified hypotheses		
Methods		
Study design: Present key elements of study design early in the paper		
Setting: Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection		
Participants: Give the eligibility criteria (i.e. age, gender, diagnosis, comorbid), and the sources (i.e. general population of a region or country) and methods of selection of participants (methods of recruitment i.e. referral, self-selection, etc.)		
Variables: Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable (i.e. home HD/high anxiety/low anxiety)		
Data Sources and measurements: For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group		
Bias: Describe any efforts to address potential sources of bias		
Study Size: Explain how the study size was arrived at		
Quantitative variables: Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why		
Statistical methods: Describe all statistical methods, including those used to control for confounding		
Describe any methods used to examine subgroups and interactions (i.e. biomarkers, type of dialysis and anxiety)		
Explain how missing data were addressed		

If applicable, describe analytical methods taking account of sampling strategy		
Describe any sensitivity analyses		
Participants		
Report numbers of individuals at each stage of study (e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed)		
Give reasons for non-participation (i.e. exclusion criteria, mental impairment, language barrier, acute illness etc.) at each stage		
Consider use of a flow diagram		
Descriptive data		
Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders		
Indicate number of participants with missing data for each variable of interest		
Outcome data		
Report numbers of outcome events or summary measures		
Main Results		
Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*Assume its unadjusted unless stated otherwise i.e. adjusted for covariates)		
Report category boundaries when continuous variables were categorized (i.e. low, medium, high scorers)		
Other Analyses		
Report other analyses done – e.g., analyses of subgroups and interactions, and sensitivity analyses (i.e. participants with low/high biomarkers is a subgroup analysis)		
Discussion		
Summarize key results with reference to study objectives		
Discuss limitations, taking into account sources of bias		
Give cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results of similar studies and other relevant evidence		
Discuss generalizability of study results		
Total Score (highest possible score 30)	/30	%

Adjusted Score (highest possible score 25 when 1) bias, 2) sample size, 3) missing data, 4) sensitivity analysis and 5) flow diagram are excluded from score as these items were often not reported.	/25	%

Scoring Key

0 = item was not completed
0.5 = item was partially completed
1 = item was completed

Table 3 Summary of Literature Review

Self-Management

Source	Sample	Study Design	Data Measurement	Major Findings	Quality Rating Unadjusted	Adjusted
Li, Jiang, & Lin (2014)	n = 198 Convenience sample from tertiary hospitals in China	Descriptive, correlational study	Hemodialysis Self-Management Instrument[a], Hemodialysis Knowledge Questionnaire, Chronic Disease Self-Efficacy Scale, Hospital Anxiety and Depression Scale, Social Support Scale	Psychological distress was negatively associated with self-management. Number of comorbidities showed negative association with problem solving subscale of self-management. Social support was positively associated with self-management.	72%	86%
a the Hemodialysis Self-Management Instrument is not available in English						
Self-Care						
Mollaoglu, M (2006)	n = 140 Hospital based hemodialysis in Turkey	Descriptive, correlational study	Multidimensional scale of perceived social support, Hamilton Anxiety Rating Scale, Exercise of Self-care Agency Scale	Statistically significant negative association between social support, anxiety and self-care agency.	68%	82%
O'Connor, Jardine, & Millar, (2008)	n = 73 Hospital-based hemodialysis in Scotland	Prospective Study	Mini Mental State Examine, End-stage renal disease severity index, Kidney Knowledge Questionnaire, Hospital Anxiety and Depression Scale, Illness Perception Questionnaire-revised,	Those using emotion-oriented coping showed poorer adherence to fluid restriction guidelines. Young men were less likely to adhere to fluid restrictions.	70%	80%

Source	Sample	Study Design	Data Measurement	Major Findings	Quality Rating Unadjusted	Quality Rating Adjusted
			Brief COPE, adherence pre-dialysis serum phosphate, interdialytic weight gain, serum potassium, dialysis adequacy			
Self-Efficacy						
Lev & Owen (1998)	n = 28 Recruited from 8 units in New Jersey, Pennslyvania, New York and Connecticut	Prospective with data collection at time 1 – 100 days of starting treatment, time 2- 4 months after starting treatment, and time 3 - 8 months after starting treatment	Strategies Used by Patients to Promote Health (a measure of self-care self-efficacy comprised of 4 subscales including coping, stress reduction, making decisions and enjoying life), Sickness Impact Profile, Profile of Mood States (measures 6 identifiable mood states: tension-anxiety, depression-dejection, anger-hostility, vigor-activity; fatigue-inertia and confusion-bewilderment), Somatic Symptom Distress Scale, Dialysis Stress Scale, Compliance Perceptions Questionnaires, End stage renal disease severity index	Greater confidence in self-efficacy abilities was associated with better mental affect, health status and adherence and lower symptom distress.	73%	84%

Source	Sample	Study Design	Data Measurement	Major Findings	Quality Rating Unadjusted	Quality Rating Adjusted
Takaki, et al. (2003)	N = 453 4 medical centers in Japan	Descriptive, correlational study	Hospital Anxiety and Depression Scale (HADS), Self-efficacy on Health-related behavior scale, Coping Inventory for Stressful Situations (CISS), How was your itchiness this last month	Higher levels of depression were associated with emotion-oriented coping. Depression was negatively associated with task orientated coping and self-efficacy. High levels of anxiety were associated with emotion-oriented coping and lower with self-efficacy.	72%	86%
Compliance/Adherence						
Christensen et al., (1995)	n = 57 2 hemo-dialysis centers affiliated with University of Iowa	Cross-sectional study	Ways of Coping Questionnaire, Adherence: interdialytic weight gain (IWG), mean IWG over 12 dialysis sessions Controllable events: fluid intake and diet, Uncontrollable events: sudden drop in BP, difficulty with needle insertion and leg cramps	Problem solving coping strategies (task-oriented) was positively correlated with adherence to fluid and diet restrictions.	84%	94%

Source	Sample	Study Design	Data Measurement	Major Findings	Quality Rating Unadjusted	Quality Rating Adjusted
Schneider et al. (1991)	n = 50 Hemodialysis centers at University hospital in New York	Cross-sectional study	Beck Depression Inventory, Spielberger Trait Anxiety Scale, Siegal Multi-dimensional Anger Inventory, Locus of Control of Behavior Scale, Somatic Symptom Distress Scale, Dialysis Stress Scale, Fluid Compliance Perceptions (4 questions developed by Rosenbaum & Ben-Ari Smira (1986), Interdialytic weight gain (used as a measure of compliance)	Based on interdialytic weight gain, no differences between depressed and non-depressed participants were found. Those with higher depressed, anxiety and anger scores reported higher symptom and dialysis stress. Depressed participants scored higher on dialysis stress scale as compared to non-depressed participants.	72%	82%
Takaki et al. (2005)	N =416 Recruited from 4 medical centers in Japan	Cross-sectional study	Hospital Anxiety and Depression Scale, Coping Inventory for Stressful Situations, dialysis adequacy	Higher levels of psychological distress was positively associated with age and emotion-orientated coping and negatively with task-oriented coping Females, lower income and education was associated with higher anxiety	60%	72%

Source	Sample	Study Design	Data Measurement	Major Findings	Quality Rating Unadjusted	Quality Rating Adjusted
Home Hemodialysis						
Nearhos, Van Eps, & Connor (2013)	N = 113 Home hemodialysis for 354 days in Brisbane, Australia	Retrospective observational cohort study	Multidimensional Health Locus of Control; COPE scale	Adaptive coping significantly supported the successful maintenance of home hemodialysis users	75%	90%

Chapter 4

Table 1. Summary of feasibility outcomes and success criteria

Feasibility Category	Source of Data	Success Criteria
Process	Recruitment rate Consent rate Completion rate	Minimum of 133 participants ≥ 50% of eligible participants ≥ 50% of all consenting participants
Resources	Missing data	< 5% missing responses per instrument

Table 2. Methods of Analysis for Instrument Development (Phase 1) and Exploratory Psychometric Evaluation (Phase 2)

Phase One: Instrument Development		
Construct	**Statistics**	**Criterion**
Item Generation	Extensive literature review	See Costantini et al. (2011) publication
Item Presentation	Conceptual analysis	Walker & Avant (2011) method of concept analysis
Item Selection	Critical analysis of existing self-management and/or self-care vascular disease instruments	Based on recommendations from Streiner & Norman (2008)
Content Validity	Content validity index	Items with Content validity index ≥ 80% were retained; items < 80% were removed or revised (Lynn, 1986)
Phase Two: Exploratory Psychometric Evaluation		
Participant Characteristics	Sociodemographics – age, gender, years diagnosed with kidney disease, years on dialysis, education, relationship status, living arrangements, caregiver support, employment, household income, presence of comorbidities, history of psychological distress and treatment	Frequencies for categorical variables Mean and standard deviation for continuous variables
Internal Consistency Reliability	Cronbach's alpha	Cronbach's alpha ≥ 0.70 (Streiner & Norman, 2008)
Test-Retest Reliability	Intraclass correlation coefficient	Intraclass correlation coefficient ≥ 0.70 (Streiner & Norman, 2008)
Exploratory Factor Analysis	Bartlett Test of Sphericity	Chi-squared and p-value > 0.05
	Kaiser-Meyer-Olkin Measure of Sampling Adequacy	Kaiser-Meyer-Olkin Measure of Sampling Adequacy > 0.70 –variable retained
	Communalities	Communalities > 0.60 – variable retained

Construct	Statistics	Criterion
Criterion Validity	Independent sample t-test Test 1. Participants with higher anxiety scores will have lower self-management scores. Test 2. Participants with task-oriented coping will demonstrate higher self-management scores. Those with emotion or avoidance coping will have lower self-management scores.	p-value > 0.05 (Norman & Streiner, 2008)

Chapter 5

Table 1. Summary of Content Validity Testing

Item	Subscale	N	% of experts correctly identified subscale	Other subscales identified by experts	Content Validity Index
1	CP	5	80%	SA = 1	1.0
2	CP	5	80%	SA = 1	1.0
3	CP	5	100%		1.0
4	CP	5	100%		1.0
5	CP	4	75%	SA = 1	1.0
6	CP	5	60%	SA = 2	1.0
7	CP	5	80%	SA = 1	1.0
8	CP	5	100%		1.0
9	CP	4	100%		1.0
10	CP	5	60%	SA = 2	1.0
11	SA	5	40%	CP = 3	1.0
12	SA	5	0	CP = 4; N = 1	1.0
13	SA	5	100%		1.0
14	SA	4	100%		1.0
15	SA	5	100%		1.0
16	SA	5	100%		1.0
17	SA	5	60%	CP = 1; IRA = 1	1.0
18	SA	5	60%	CP = 2	1.0
19	SM	5	100%		1.0
20	SM	5	80%	CP = 1	1.0
21	SM	5	80%	SA = 1	1.0
22	SM	4	100%		1.0
23	SM	5	80%	IRA = 1	1.0
24	SM	5	100%		1.0
25	SM	5	20%	SA = 1; IRA = 3	1.0
26	SM	5	0	IRA = 5	1.0
27	SM	5	100%		1.0
28	SM	5	60%	SA = 1; IRA = 1	1.0
29	SM	5	40%	SA = 2; N = 1	1.0
30	SM	5	80%	SA = 1	1.0
31	SM	4	75%	SA = 1	1.0
32	IRA	5	60%	SA = 1; SM =1	1.0
33	IRA	5	100%		1.0
34	IRA	5	60%	SA = 1; SM = 1	1.0
35	IRA	5	80%	CP = 1	1.0
36	IRA	5	40%	SM = 3	1.0
37	IRA	5	40%	SM =3	1.0

Item	Subscale	N	% of experts correctly identified subscale	Other subscales identified by experts	Content Validity Index
38	IRA	5	20%	SM = 4	1.0
39	IRA	5	0	SA = 2; SM = 3	0.80
40	IRA	5	20%	SM = 4	1.0
41	IRA	5	100%		1.0
42	IRA	5	100%		1.0
43	IRA	5	40%	CP = 3	1.0
44	IRA	4	0	CP = 3; SA = 1	1.0
45	N	5	100%		1.0
46	N	5	80%	SA =1	1.0
47	N	5	100%		0.80
48	N	5	40%	IRA = 3	1.0
49	N	5	80%	SA = 1	0.60
50	N	5	80%	IRA = 1	1.0
51	N	5	100%		1.0
52	N	5	60%	IRA = 2	1.0
53	N	5	60%	SM =1; IRA = 1	1.0
54	N	5	100%	100%	1.0

CP = Collaborative partnerships; SA = Self-advocacy; SM = Self-monitoring; IRA = Illness-related activities; N = Normalizing

Table 2. Study flow diagram (October 2014 to April 2015)

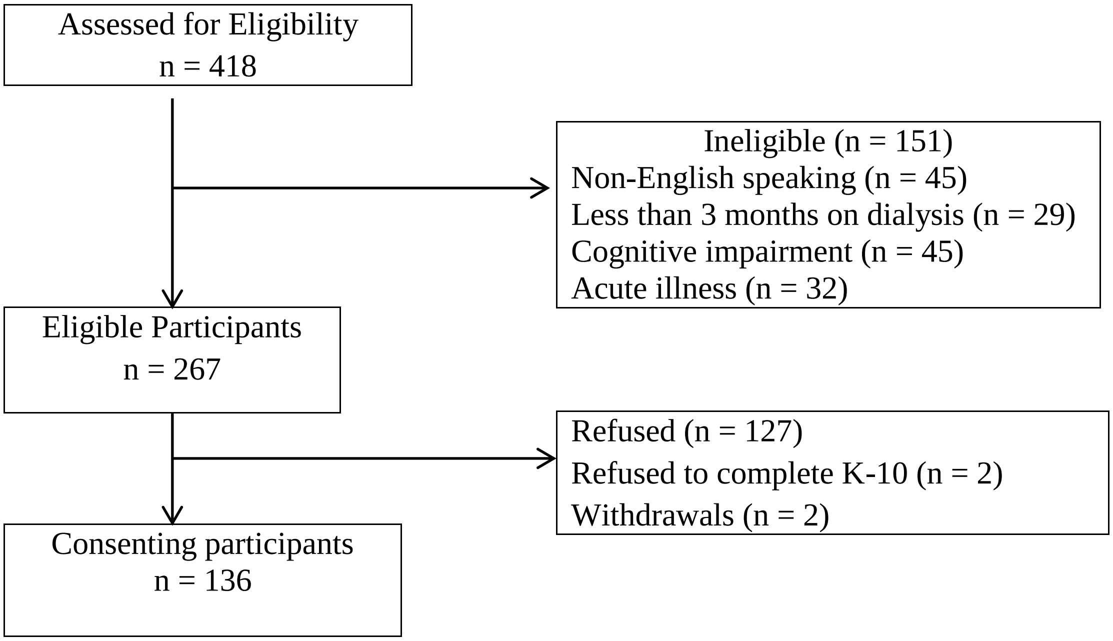


Table 3. Summary of feasibility outcomes

Data Source	Criteria	Feasibility Outcomes	Success
Recruitment rate	Minimum of 133 participants	n = 140 (140/267 = 52%)	Yes
Consent rate	≥ 50% of eligible participants	n = 136 (140 – 4 withdrew = 136/267) = 51%	Yes
Completion rate*	≥ 50% of all consenting participants	n = 44 (44/136) = 31.62%	No
Missing data	< 5% missing responses per instrument	K- 10 – 1.47% CISS-SSC – 1.16% VSMI – 1.42%	Yes Yes Yes

***** Percentage of participants that completed initial questionnaires package and re-test

Table 4. Sociodemographic variables based on the total, in-center/satellite and home hemodialysis study participants

Characteristics	Total (n = 136)		In-center/ Satellite (n = 123)		Home Hemodialysis (n = 13)	
	n	%	n	%	n	%
Age						
20 – 39	8	5.7%	6	4.8%	2	15.4%
40 – 59	44	32.5%	41	33.3%	3	23.1%
60 – 79	68	49.9%	61	49.8%	7	53.9%
80 & over	16	11.9%	15	12.1%	1	7.7%
Gender						
Male	83	61.0%	72	58.5%	11	84.6%
Female	53	39.0%	51	41.5%	2	15.4%
Year dx with kidney disease[a]						
2005 – 2015	81	59.6%	74	60.3%	7	53.9%
1970 - 2004	45	32.6%	39	39.7%	6	46.2%
Year on dialysis[b]						
2005 – 2015	116	83.0%	102	83.0%	12	93.3%
2004 – 1978	19	13.8%	18	14.6%	0	0.0%
Education						
Grade school	16	11.8%	16	13.0%	0	0.0%
High school	49	36.0%	45	36.6%	4	30.8%
Post-secondary	71	52.2%	62	50.4%	9	69.3%
Relationship Status						
Single	23	16.9%	23	18.7%	0	0.0%
Married/common-law	73	53.7%	62	50.4%	11	84.6%
Divorced/widowed	40	29.5%	38	30.9%	2	15.4%
Living Arrangements						
Alone	41	30.1%	40	32.5%	1	7.7%
Spouse/partner	72	52.9%	62	50.4%	10	76.9%
Other	23	16.8%	21	17.1%	2	15.4%
Caregiver Support						
Yes	100	73.5%	90	73.2%	10	76.9%
No	36	26.5%	33	26.8%	3	23.1%
Employment Status						
Long-term disability	47	34.6%	41	33.3%	6	46.2%
Retired	66	48.5%	62	50.4%	4	30.8%
Employed (full/part-time)	16	11.8%	13	10.6%	3	23.1%
Other	7	5.1%	7	5.7%	0	0.0%
Household Income						
< $25,000	44	32.4%	43	35.0%	1	7.7%
$25,000 - $50,000	45	33.1%	40	32.5%	5	38.5%
> $51,000	29	21.3%	22	17.9%	7	53.9%

Not specified		18	13.2%	18	14.6%	0	0.0%
Presence of Comorbidities							
Cardiovascular disease		2	1.5%	2	1.6%	0	0.0%
Hypertension		12	8.8%	12	9.8%	0	0.0%
Insulin dependent diabetes		1	0.7%	0	0.0%	1	7.7%
Multiple vascular diseases[c]		32	23.5%	29	23.6%	3	23.1%
Vascular and other illnesses		63	46.3%	58	47.2%	5	38.5%
Other illnesses only[d]		14	10.3%	12	9.8%	2	15.4%
None		12	8.8%	10	8.1%	2	15.4%
Psychological Distress							
Anxiety	Yes	31	22.8%	29	23.6%	2	15.4%
	No	105	77.2%	94	76.4%	11	84.6%
Depression	Yes	31	22.8%	28	22.8%	3	23.1%
	No	105	77.2%	95	77.2%	10	76.9%
Treatment							
Medication		19	14.0%	18	14.7%	1	7.7%
Counseling		10	7.3%	9	7.7%	1	7.7%
Both		29	21.3%	26	21.3%	3	23.1%
		Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
Age		61.59	14.02	61.94	14.05	58.31	13.88
Years of education		13.62	2.77	13.50	2.82	14.77	1.92
Years dx with kidney disease		12.07	11.43	11.72	11.23	15.15	13.34
Years on dialysis		5.67	6.18	5.93	6.41	3.08	1.44
Number of comorbidities		2.60	1.64	2.61	1.61	2.54	1.94

a Missing data n = 126; b Missing data n = 1; c Multiple vascular disease combination of cardiovascular, hypertension, and/or diabetes; d Other illnesses included stroke, arthritis, lung disease and cancer

Table 5. Comparison of unadjusted scores for the K-10 and CISS:SSC of all study participants versus in-center/satellite and home hemodialysis

	Total (n = 136)		In-center/ Satellite (n = 123)		Home Hemodialysis (n = 13)	
	n	%	n	%	n	%
K-10						
Low risk (10-15)	57	41.9%	51	41.5%	6	46.2%
Medium risk (16-29)	68	50.0%	61	49.6%	7	53.8%
High risk (30-50)	11	8.1%	11	8.9%	0	0.0%
CISS: SSC						
TOC	20	14.7%	16	13.0%	4	30.8%
EOC	30	22.1%	29	23.6%	1	7.7%
AOC	69	50.7%	64	52.0%	5	38.5%
EOC & AOC	17	12.5%	14	11.4%	3	23.1%

TOC = Task-oriented coping, EOC = Emotion-oriented coping, AOC = Avoidance-oriented coping

Table 6. Reliability based on the subscales of the VSMI

Subscale	n	Cronbach's Alpha	Standardized Item Cronbach's Alpha
Collaborative Partnerships	123	0.868	0.871
Self-Advocacy	123	0.715	0.721
Self-Monitoring	110	0.849	0.854
Illness-Related Activities	129	0.674	0.671
Normalcy	125	0.798	0.800

Table 7. Mean, Variance, Item correlation and Cronbach's Alpha for each item of the VSMI

Collaborative Partnerships

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	46.56	125.95	0.602	0.504	0.854
2	46.40	122.46	0.686	0.610	0.847
3	45.26	139.28	0.477	0.478	0.864
4	45.45	136.59	0.502	0.528	0.862
5	46.66	124.08	0.657	0.488	0.849
6	47.39	124.44	0.641	0.538	0.851
7	46.90	124.79	0.630	0.550	0.852
8	46.45	126.68	0.587	0.436	0.855
9	45.10	140.06	0.545	0.446	0.861
10	46.79	124.96	0.551	0.397	0.860

Self-Advocacy

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	25.39	65.24	0.472	0.430	0.667
2	25.97	61.90	0.485	0.464	0.659
3	26.39	68.60	0.208	0.111	0.719
4	28.01	59.40	0.450	0.223	0.665
5	27.65	61.71	0.453	0.276	0.665
6	27.68	61.78	0.434	0.228	0.670
7	27.24	60.09	0.432	0.253	0.670
8	29.19	70.50	0.271	0.127	0.701

Self-Monitoring

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	68.75	152.80	0.404	0.389	0.729
2	67.28	148.92	0.648	0.602	0.714
3	67.75	145.59	0.572	0.523	0.713
4	67.77	153.21	0.523	0.528	0.723
5	67.46	151.26	0.411	0.409	0.728
6	67.03	154.06	0.491	0.403	0.726
7	67.42	149.88	0.434	0.274	0.725
8	67.92	147.91	0.508	0.518	0.719

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
9	67.05	156.22	0.389	0.399	0.732
10	67.46	148.62	0.506	0.444	0.720
11	68.25	151.43	0.446	0.334	0.725
12	67.73	146.71	0.502	0.414	0.718
13	66.86	129.02	0.156	0.061	0.849

Illness-Related Activities

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	51.75	85.99	0.319	0.195	0.684
2	50.39	90.87	0.269	0.218	0.689
3	50.61	87.51	0.255	0.219	0.702
4	50.84	86.95	0.405	0.298	0.671
5	49.85	89.10	0.315	0.432	0.683
6	49.75	87.99	0.446	0.484	0.668
7	53.02	78.35	0.434	0.350	0.664
8	53.28	81.96	0.411	0.319	0.668
9	49.28	95.94	0.295	0.243	0.690
10	51.30	84.19	0.407	0.348	0.669
11	54.20	96.54	0.110	0.037	0.707
12	50.20	85.93	0.446	0.314	0.666

Normalcy

Item	Scale Mean if Item Deleted	Scale Variance If Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
1	45.14	86.06	0.516	0.316	0.736
2	44.59	90.98	0.390	0.204	0.751
3	44.76	82.53	0.524	0.369	0.732
4	44.44	87.31	0.497	0.303	0.739
5	46.83	84.57	0.344	0.232	0.762
6	45.01	84.48	0.592	0.384	0.727
7	44.94	84.40	0.484	0.382	0.738
8	45.97	83.82	0.479	0.280	0.738
9	45.46	86.45	0.434	0.244	0.745
10	47.41	91.52	0.181	0.115	0.786

Table 8. Items removed based on low Mean Sampling Adequacy and Communalities

Variable	Mean Sampling Adequacy	Communality
I seek out written information about my illness and treatment.	0.598	
I figure out ways to make sure that my dialysis access site is protected.	0.648	
When necessary, I figure out other ways to get the care I need.	0.657	
I try to be positive about my life in spite of my illness.		0.488
I can usually figure out the reasons for changes symptoms.		0.562
I think of my dialysis treatments as a way to stay healthy.		0.489
I follow a routine that fits with my preferred lifestyle.		0.499
I pay attention to blood laboratory results.		0.544
I can figure out ways to manage my fatigue.		0.543

Table 9. Total Variance Explained

		Initial Eigenvalues[a]			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings[b]
	Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
Raw	1	30.276	34.814	34.814	30.276	34.814	34.814	23.216
	2	6.685	7.686	42.500	6.685	7.686	42.500	16.470
	3	6.378	7.334	49.834	6.378	7.334	49.834	20.613
	4	4.891	5.625	55.459	4.891	5.625	55.459	12.815
	5	4.372	5.027	60.486	4.372	5.027	60.486	8.027
	6	3.740	4.300	64.786	3.740	4.300	64.786	11.966

Extraction Method: Principal Component Analysis.

When analyzing a covariance matrix, the initial eigenvalues are the same across the raw and rescaled solution.$_a$

When components are correlated, sums of squared loadings cannot be added to obtain a total variance.$_b$

Table 10. Factors and Significant Factor Loadings

	Significant Factor Loadings					
Factors	F1	F2	F3	F4	F5	F6
Collaborative Partnerships						
I am comfortable talking to my health care providers about ways to change my care to better fit with my everyday life.	0.864					
I ask my health care providers for information about my treatment.	0.852					
I am comfortable telling my health care providers which treatment recommendations work best for me.	0.824					
I ask my health care providers for information about my illness.	0.724					
I pay attention to events in my every day life that may cause my illness to get worse.	0.618					
I am comfortable talking to my health care providers about my illness.	0.562					
I am comfortable talking to my health care provider about my treatment plan.	0.560					
I pay attention to how my dialysis treatment makes me feel.	0.521					
Self-Monitoring						
I pay attention to the foods I choose to eat.		0.691				
I pay attention to how much weight I gain between dialysis treatments.		0.674				
I drink fluids as suggested by my health care providers.		0.642				
I adjust my eating to fit with other areas activities.		0.641				
I change how much fluid I drink to fit with my every day life.		0.634				
Self-Advocacy						
I talk to other patients on dialysis for information about the illness and treatment.			0.893			
I talk to my health care providers about goals I would like to accomplish to improve my health.			0.846			
I talk to my health care providers to figure out ways to manage symptoms.			0.743			

Factors	F1	F2	F3	F4	F5	F6
I talk to my health care providers to figure out ways to change my treatment plan when necessary.			0.572			
Normalcy						
I figure out ways to fit my dialysis therapy into my everyday life.				0.809		
I try to find ways that make my life as normal as possible.				0.664		
I adjust other responsibilities in my life to fit with my dialysis treatment schedule.				0.595		
Illness-Related Activities						
I keep a record of my blood pressure readings.					0.724	
I keep a record of how much fluid I gain between dialysis treatments.					0.714	
Factor Not Defined A Priori						
I look for information on the internet about my illness and treatment.						0.905
I can figure out which symptoms tell me the most about my illness.						0.529

Table 11. Summary of criterion-related validity tests

Criterion Validity Test 1	**n**	**Mean**	**SD**	**t-test**	**df**	**p-value**
K-10 score Low risk	57	256.75	48.53	-0.007	134	0.995
K-10 score Moderate to high risk	79	256.81	49.41			
Criterion Validity Test 2						
CISS: SSC Task-oriented coping	20	283.75	32.10	2.736	134	0.007
CISS: SSC Emotion and Avoidance	116	252.14	49.83			

Appendix A - Measurement of self-management for adults with vascular diseases: A critical analysis

McMaster University
Nursing Graduate Program
PhD Comprehensive Examination Outline

Area B:
Research Methods-Related Issue

Measurement of self-management for adults with vascular diseases: A critical analysis

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Introduction

Self-management is a difficult concept to operationalize and measure for adults with vascular conditions (cardiovascular disease, diabetes, chronic kidney disease). Researchers often use other constructs such as quality of life, illness perception, and health belief to evaluate self-management interventions and health outcomes (Boyde, Turner, Thompson & Stewart, 2011; Chan, Wong & Chow, 2010; Chen, Tsai & Lee, 2009; Powers, Olsen, Oddone & Bosworth, 2009; Su, Lu, Chen & Wang, 2009). The heterogeneity of measurement tools makes comparative analysis difficult. Addressing this gap within the literature is important, as self-management has been integrated into many health care services in an effort to improve patient outcomes (Toobert, Hampson & Glasgow, 2000). For example, the American Diabetes Association has established the national standard for diabetes self-management education (Funnell et al., 2008). In Canada, the Ontario Renal Network has made increasing the number of patients using home-based dialysis therapy a strategic goal for the province (Visaya, 2010). Therefore, reliable and valid tools that measure the self-management of vascular diseases is essential to assess patient behaviors and evaluate programs.

Clear delineation of self-management is necessary to support accurate measurement. This is particularly challenging as the terminology, definitions and conceptualization of self-management are confusing. Several terms including self-management, self-care, self-monitor, compliance, and adherence are often used interchangeably (Case Western Reserve University, 2009; Chan et al., 2010; Du et al., 2011; Lin, Cavendish, Boren, Ofstad & Seidensticker, 2008; Scollan-Koliopoulos &

Walker, 2009). The seminal writings of Orem (1985; 1995) on self-care and Lorig (2003) on self-management provide some clarity. Orem defined the concept of self-care as human beings attention to and management of themselves. The conceptual components of Orem's self-care theory are; i) self-care defined as the active participation in result seeking tasks that attain and maintain health, ii) self-care agency is the capacity to engage in behaviors and activities that promote health, and iii) self-care requisites are the regulatory functions needed to support human development and alleviate or minimize poor health outcomes. According to Orem self-care must be incorporated into the person's life and requires support from health care providers, family and friends (Denyes, Orem & Sozwiss, 2001; Orem, 1985; Orem, 1995). Self-management, as conceived by Lorig and colleagues (2003; 2001; 1999) encompasses five core skills including; i) problem solving the physical and mental issues associated with the illness such as medication side effects and anxiety or depression, ii) decision-making is necessary on a daily basis to manage fluctuations of symptoms, iii) resource utilization provides information through the internet, library or community services, iv) partnering with family, friends and health care providers to garner support, and v) taking action is the to-do list of tasks required to implement treatment regimes and other related activities (Lorig & Holman, 2003; Lorig et al., 2001; Lorig et al., 1999). Additionally, Lorig and Holman (2003) stated that self-efficacy is needed as patients must be confident in their ability to engage in self-management.

Given the multidimensional nature of self-care and self-management, it is not surprising to find inconsistencies in the literature (Embrey, 2006; Hughes, 2010). Close examination of the attributes described by Orem and Lorig indicated similarities between self-care and self-management (Lorig & Holman, 2003; Lorig et al., 2001; Orem, 1985; Orem, 1995; Denyes et al., 2001). Others contend that adherence, which is the obedience to the prescribed treatment regime, adequately quantifies self-care and/or self-management (Toobert & Glasgow, 1994). The debate regarding the conceptualization of self-care, self-management and related terms is ongoing within the literature and beyond the scope of this paper. The aims of this paper were threefold: to critically analyze the psychometric properties of instruments that measure the self-care or self-management of adults with vascular conditions using Streiner and Norman (2008), ascertain whether these measurement tools are consistent with the conceptualization of self-care or self-management as described by Orem and Lorig, and discuss implications for nursing research, policy and practice.

Methods

Search Strategy

Several search strategies were employed to facilitate comprehensive review of the literature. The search engines Health and Psychosocial Instruments and Medline were used to obtain articles from 1980 to 2012. The following search terms supported literature extraction; self-care, self-manage, cardiovascular disease, heart disease, hypertension, diabetes (type I and type II), renal insufficiency, kidney disease, end stage renal disease, psychometrics, content validity, construct validity, tools, questionnaires and instruments. These terms were combined and exploded to include all subheadings. The reference lists of relevant articles were examined to locate additional publications. Google scholar was utilized to explore the literature for dissertations and conference abstracts. Documents were selected based on the following inclusion/exclusion criteria; i) the intended purpose of the instrument was to measure self-care or self-management for adults with a vascular condition (heart disease, diabetes or chronic kidney disease), ii) articles must describe the development and psychometric evaluation of the tools, and iii) publications must be available in English. Tools that combined the term self-management and/or self-care with other concepts such as, knowledge were excluded. Instruments measuring children, adolescents or lay-caregiver self-management were not considered in this analysis.

Instrument Selection

The following tools met all the above inclusion/exclusion criteria; 1) Self-Care of Heart Failure Index (SCHFI) (Riegel, Carlson, & Glaser, 2000; Riegel et al., 2004; Riegel, Lee, Dickson & Carlson, 2009), 2) European Heart Failure Self-Care Behaviour scale (EHFScB) (Jaarsma, Arestedt, Martensson, Dracup & Stromberg, 2009; Jaarsma, Stromberg, Martensson & Dracup, 2003), 3) Summary of Diabetes Self-Care Activities scale (SDSCA) (Toobert & Glasgow, 1994; Toobert, Hampson & Glasgow, 2000), and 4) Diabetes Self-Management Instrument (DSMI) (Lin, Anderson, Chang, Hagerty & Loveland-Cherry, 2008; Lin, 2005). For cardiovascular disease, tools that measured the self-management of hypertension were preferable, as the condition often coexists with other vascular diseases. (Canadian Organ Replacement Register, 2011; Cardiac Care Network of Ontario, 2012). None were found in the literature instead, instruments measuring the self-management of heart failure were evaluated. The SCHFI has undergone initial testing and revisions permitting greater depth of analysis (Riegel et al., 2000; Riegel et al., 2004; Riegel et al., 2009). The EHFScB scale was developed and tested in several different languages including English. The ability to speak and read English is often an inclusion criterion for many investigations, potentially generating selection bias of study participants. As such, reliable and validated tools available in other languages are important, particularly in Canada where fluency in other languages is high (Jaarsma et al., 2009; Jaarsma et al., 2003). The SDSCA is a widely used tool that has been evaluated in numerous intervention and observational studies (Toobert & Glasgow, 1994; Toobert et al., 2000). The DSMI was recently developed making it an interesting comparator to the SDSCA scale (Lin, 2005). The Diabetes Self-Care Inventory was excluded since it measures perceived adherence to self-care recommendations as opposed to self-care (Weinger, Butler, Welch & La Greca, 2005).

Numerous exceptions regarding the inclusion/exclusion criteria were necessary for instruments measuring the self-management of chronic kidney disease. The only tools found in the literature that have undergone developmental and psychometric assessment were the Chronic Kidney Disease Self-Efficacy Instrument (CKD-SE) (Lin et al., 2012) and End Stage Renal Disease Adherence Questionnaire (ESRD-AQ) (Kim, Evangelista, Phillips, Pavlish & Kopple, 2010). All tools included in this analysis were self-report instruments.

Evaluation Criteria

The Streiner and Norman (2008) text was used in consultation with expert nursing professors to develop evaluation criteria for the instruments (see Appendix A and B). Six key areas were examined these included reliability, content validity, construct validity, predicative validity, discriminatory ability and practical properties. The assessment of reliability was based on sampling methods, internal consistency and stability measurement (test-retest). Sampling provides information regarding the appropriate utilization of the tool for specific disease conditions (Streiner & Norman, 2008; Streiner & Norman, 2009). Ranking the internal consistency as good (0.70), commendable (0.80) and strong (0.90) was used to evaluate the tools. A ranking of good is recommended to use the tool for basic research and strong for application in clinical settings. Coefficient alphas exceeding 0.90 suggest redundancy necessitating removal of some items from the tool (Streiner & Norman, 2008). Stability measurements or test-retest reliability examine the reproducibility of the results when a tool is administered on different occasions. This approach involves re-administering the same instrument 2 to 14 days apart (Streiner & Norman, 2008). Streiner and Norman (2008) suggested that an Intraclass correlation coefficient (ICC) of 0.70 was acceptable for relatively stable traits. Self-management may fluctuate over time due to several factors including illness severity, social support or financial resources (Chan et al., 2010; Loos-Ayav et al., 2008). Therefore, stability measurements in the low 0.70s were considered adequate (Streiner & Norman, 2008).

Content validity examines the relevance of items within the tool by using a two-stage process that includes the development and judgment phase. The development stage consists of three steps, identification of content domain, generating items, and assembling the items into a usable format. The judgment phase requires consultation with content experts and calculation of the content validity index (CVI) (Lynn, 1986). Numerous health care professionals with expertise in self-management and vascular disease were accessible for consultation, as such a minimum of five experts is recommended (Costantini, Beanlands, & Horsburgh, 2011; Lin, 2005; Toobert & Glasgow, 1994). The CVI is determined by asking experts to rate the content relevance of each item using a 4-point Likert scale where 1 is irrelevant and 4 is extremely relevant. Items should receive a rating of 3 or 4 to be considered relevant for the tool. The CVI is calculated by totaling the proportion of all items deemed relevant. Three questions facilitated the analysis of content validity (Lynn, 1986).

Construct validity involves "linking the attribute we are measuring to some other attribute by a hypothesis or construct" (Streiner & Norman, 2008, p. 10). The attributes associated with the measurement of self-management and their consistency with Orem's self-care theory and Lorig's writings on self-management were analyzed. The work of Orem and Lorig were selected as the standard for comparison. These authors have extensively studied self-care and self-management and contributed seminal literature widely used by nurse researchers and scholars (Denyes et al., 2001; Dodd & Dibble, 1993; Orem, 1985; Orem, 1995; Lorig & Holman, 2003; Lorig et al., 2001; Lorig et al., 1999; Streiner & Norman, 2008). Further the type of construct validity was identified for example, criterion, concurrent, convergent, and divergent. When tools were compared to another instrument the strength of the correlation was evaluated. Correlations between 0.70 to 0.90 were considered strong, 0.40 to 0.60 moderate and 0.10 to 0.30 weak (Streiner & Norman, 2008; Streiner & Norman, 2009).

Predictive validity is a type of construct validity concerned with the instrument's ability to predict a future health outcome. For example, a hospital would like to know how many chronic kidney disease patients would choose a home-based dialysis therapy. Administer a tool that measures self-management to stage 3 and 4 chronic kidney disease patients prior to commencing a dialysis therapy. Once the patients have started dialysis approximately one year later determine how many patients selected a home-based therapy versus in-center dialysis (Butt, 2006; Streiner & Norman, 2008).

The discriminatory ability of an instrument distinguishes between those who score higher and should have better self-management abilities and those who score lower and are poor self-managers. This is vital when determining the effectiveness of nursing interventions and services. Cross-sectional studies are used to evaluate discriminatory ability by comparing different groups of patients known to have the trait. For example, patients that dialyze at home should exhibit high scores versus those using in-center dialysis (Butt, 2006; Streiner & Norman, 2008).

Practical properties are important to consider when deciding which tool should be administered to a study sample. The length of time to complete the tool and readability must fit the setting and patient abilities. The table in Appendix A explicates the response format used for the evaluative components and Appendix B summarizes the findings of this analysis (Butt, 2006; Streiner & Norman, 2008).

Results

Self-care of Heart Failure Index (SCHFI)

The SCHFI is a 15-item tool designed to measure the self-care of adults with heart failure. Higher instrument scores indicate better self-care. It is available in English and Spanish (Riegel et al., 2004). The tool was original named the Self-Management of Heart

Failure Index and reliability testing was completed on a homogeneous sample of 127 elderly (70 years and older) patients diagnosed with heart failure. The items and response format were modified following initial testing to strengthen the internal consistency of the tool (Riegel et al., 2000). The revised version of the SCHFI underwent reliability testing with a convenience sample of 760 heart failure patients from seven hospitals across the United States. On average subjects were 70 years of age and had been diagnosed with heart failure for more than 2 months (69%). Internal consistency testing demonstrated good reliability ($a = 0.76$) of the SCHFI. The authors of the tool did not complete stability testing (Riegel et al., 2004; Streiner & Norman, 2008).

Content validity testing was conducted using the Self-Management Heart Failure Index and included the development phase only. An extensive literature search and data from semi-structured interviews with 25 heart failure patients generated content domain and items for the tool. Four cardiovascular experts reviewed these findings to further support tool development. The ranking of item relevance was not completed, as such the content validity index was not known (Lynn, 1986; Riegel et al., 2000).

Riegel et al (2000) stated that self-management is one component of the broader construct of self-care. Several attributes consistent with self-management and self-care theory were identified. These included decision-making, problem solving (Lorig & Holman, 2003), symptom monitoring (Denyes et al., 2001; Orem & Vardiman, 1995), treatment implementation and evaluation (Lorig et al., 1999) and self-confidence (Lorig & Holman, 2003).

Riegel et al (2004) evaluated known-groups validity also referred to as criterion-related validity (DeVellis, 2012; Streiner & Norman, 2008). Subjects were divided into two groups, those diagnosed less than 2 months ago and greater than 2 months ago. It was hypothesized that those diagnosed for longer periods of time would demonstrate higher self-care scores. Unpaired sample t-tests showed that those diagnosed for longer periods of time had better self-care scores ($t=2.1$, $p>0.04$) (Riegel et al., 2004). Predictive validity, discriminatory ability and readability were not reported. The tool takes approximately 5 minutes to complete (Streiner & Norman, 2008).

European Heart Failure Self-care Behaviour Scale (EHFScB)

The EHFScB measures the self-care behaviors of adults with heart failure. Originally the tool was developed as a 20-item scale available in Dutch and translated into English and Swedish. This version underwent psychometric evaluation and was used in two interventional studies, all with elderly heart failure patients (Jaarsma et al., 2003; Shuldham, Theaker, Jaarsma & Cowie, 2007). The revised 12-item EHFScB scale is available in 14 different languages (British and American English, Dutch, Swedish, Italian, Spanish, Catalan, German, Finnish, Danish, Hebrew, Lithuanian, Chinese and Japanese). Additional revisions included a 9-item version of the tool (Jaarsma et al., 2009). The 12-item EHFScB scale was reported here, as more psychometric information was available. Lower instrument scores suggest good self-care (Jaarsma et al., 2003).

A pooled convenience sample of 2592 patients with heart failure were recruited from hospitals and clinics in the Netherlands, Spain, Germany, United Kingdom, Italy, and Sweden. Subjects ranged in age from 64 to 79 years and based on the New York

Heart Association Functional Classification (NYHA) illness severity varied from mild symptoms to marked limitations (see Appendix C). Reliability testing demonstrated good internal consistency ($a = 0.77$) (Jaarsma et al., 2009). Shuldham et al (2007) evaluated stability (n=183) with predominately male heart failure subjects from the United Kingdom. A Bland-Altman plot demonstrated acceptable retest reliability at 2-weeks and differences between scores was -0.5 (Shuldham et al., 2007; Streiner & Norman, 2008).

Content validity was conducted several times with international heart failure experts. For the original tool, the steps followed to assess content validity testing were not described in the literature (Jaarsma et al., 2003). Additional assessment of content validity was conducted on the 12-item EHFScB scale with a panel of 10 heart failure experts. These experts completed an open-ended questionnaire on the completeness of the scale. The rating of item relevance and content validity index was not done. The versions available in different languages were back translated to ensure semantic and cultural sensitivity equivalence (Jaarsma et al., 2009).

The original EHFScB scale was theoretically based on Orem’s self-care theory (Jaarsma et al., 2003). The attributes included managing fluid, diet, medication and preventative treatment regimes, seeking assistance from health care providers and lifestyle adjustment that fit with illness demands (Orem, 1985; Orem 1995). Thus, the tool incorporated several characteristics consistent with self-care theory (Jaarsma et al., 2003).

Construct validity was evaluated using convergent and divergent testing. Convergent validity was evaluated by comparing the EHFScB scale with the Heart

Failure Compliance Questionnaire. The weak correlation may suggest that these tools measured similar constructs (*r*=0.32, p<0.001). The Minnesota Living with Heart Failure Questionnaire measures quality of life. Divergent validity was evident indicating that self-care and quality of life are distinct concepts (*r*=0.01, p<0.001) (Jaarsma et al., 2009). Other researchers assessed the concurrent validity of the EHFScB scale with the SCHFI (n = 183) and found a weak, non-significant correlation between scores (*r*=0.09, p=0.25) (Shuldham et al., 2007). Gonzalez et al (2006) assessed the predictive validity of the Spanish version of the EHFScB scale (n = 335) at 1, 3, 6, 9, 12 and 15 months. Instrument scores improved significantly suggesting the tool detects changes over time (*r*=-0.37, p<0.001). Data on discriminator ability and readability was not found in the literature (Streiner & Norman, 2008).

Summary of Diabetes Self-care Activities Scale (SDSCA)

The SDSCA scale is a widely used self-report instrument designed to measure specific aspects of self-care for people with diabetes. The tool consists of 25-items and higher scores suggest better self-care. Originally the SDSCA was developed in the early 1980s for people with type I diabetes and has since been revised to include people with type II diabetes. The tool includes items that addressed diet, exercise, blood glucose monitoring, foot care and smoking. The later two components were added to reflect current diabetes clinical guidelines (Toobert & Glasgow, 1994). The SDSCA has been translated into Spanish and Korean (Choi et al., 2011; Vincent, McEwen & Pasvogel, 2008).

Toobert et al (2000) provided a comprehensive review of five intervention and two observational studies that used the SDSCA scale. Data from these studies were pooled to conduct psychometric evaluation of the scale. Collectively these studies consisted of 1988 subjects with type II diabetes between the ages of 45 and 67 years. The mean internal consistency of the tool was calculated by averaging the inter-item correlations, which was moderate (0.47). Stability measures varied when assessed over 3 to 4 months ($r=-0.05$ to 0.78, $p<0.01$, $p<0.001$). The wording on the SDSCA scale differed slightly across studies. Some researchers did not include data on the foot care and smoking subscales (Streiner & Norman, 2008; Toobert et al., 2000).

Content validity testing was conducted using a panel of experts that compiled medical research on patient compliance to generate content domains and items. The Delphi technique was used to evaluate the tool. The number of experts and professional designations were not reported (Toobert & Glasgow, 1994).

Toobert & Glasgow (1994) used compliance, adherence, self-management and self-care interchangeably when describing the attributes of the tool. Self-care was defined as the level of consistency with the prescribed treatment regimes and compliance compares patients' behaviors to medical recommendations (Toobert & Glasgow, 1994). The distinction between terms is not clear. It seems that the SDSCA scale measures compliance and/or adherence as opposed to the broader constructs of self-management (Embrey, 2006; Hughes, 2010; Rothenberger, 2011).

Concurrent validity was assessed for the diet and exercise subscales of the tool using criterion measures that included the Food Habits Questionnaire, Block Fat

Screener, Stanford 7-Day Recall, Physical Activity Scale for the Elderly, food records, and exercise logs. Weak to moderately strong correlations were reported (r=-0.23 to 0.58, p<0.01,p<0.05, p<0.001) (Toobert et al., 2000). Others evaluated criterion validity through comparison with glycosated hemoglobin and found non-significant correlations. However, poor blood glucose control was associated with lower SDSCA scores supporting weak evidence of criterion validity (Wangberg, 2008). Data on predictive validity, discriminatory ability and readability was not reported in the literature (Streiner & Norman, 2008).

Diabetes Self-Management Instrument (DSMI)

The DSMI is a 35-item tool that measures the self-management behaviors of adults with type II diabetes. Higher scores indicated better self-management. The tool is available in English and Chinese. Reliability testing was conducted using the Chinese version and subjects were recruited from three hospitals in Southern Taiwan. The nonrandom sample consisted of 634 people with type II diabetes ranging in age from 20 to 88 years. The majority of subjects' required oral hypoglycemic medications (81%) (Lin, 2005). Strong internal consistency ($a = 0.94$) of the DSMI was evident. The test-retest reliability (n = 22) was acceptable (r=0.73, $p < 0.001$) when re-administered two weeks apart (Lin, 2005; Streiner & Norman, 2008).

Content validity testing of the DSMI was conducted using the English version. The developmental phase included extensive literature review and qualitative research with focus groups. The study explored the self-management perspectives and strategies of 41 participants from Taiwan diagnosed with type II diabetes. The judgment phase was completed through consultation with seven diabetes experts (physicians and nurse practitioners). The CVI was 0.90 (Lin, 2005; Lynn, 1986).

The attributes associated with the DSMI were consistent with self-management and self-care theory (Lorig & Holman, 2003; Orem, 1985). These included 'self-regulation' described as the process of developing strategies and goals to achieve desired disease outcomes (Lorig & Holman, 2003), 'self-integration' is balancing the treatment regime with preferred lifestyle (Denyes et al., 2001; Orem, 1985), 'collaborating with health care providers and significant others' is self explanatory (Denyes et al., 2001; Lorig et al., 1999; Orem, 1985) and 'preventative and therapeutic health-related activities' involves monitoring blood glucose and following the treatment regime (Denyes et al., 2001; Orem, 1985). Though the terms used to describe the attributes vary, the definitions are similar to the theoretical foundations of self-management and self-care (Denyes et al., 2001; Lorig & Holman, 2003; Orem, 1985).

Different types of construct validity were tested. Lin (2005) stated that comparing the DSMI with the SDSCA tested divergent validity, as self-management and self-care are similar but different constructs (n = 634). The resultant positive, moderately strong correlation between the tools (r=0.55, p<0.001) indicates convergent validity (Streiner & Norman, 2008). Criterion validity was examined using glycosated hemoglobin and DSMI scores. A statistically significant negative correlation (r= -0.16, p<0.001) showed that those with lower blood glucose scored higher on the DSMI. The strength of this relationship was weak. Other validation tests included comparison with the Diabetes Empowerment Scale – Short Form. Results showed that subjects with higher empowerment scores also had higher DSMI scores (t-test=15.21, p<0.001). Predictive validity, discriminatory ability and readability of the DSMI were not reported (Lin, 2005; Streiner & Norman, 2008).

Chronic Kidney Disease Self-Efficacy Instrument (CKD-SE)

The CKD-SE is a 25-item instrument aimed at measuring disease specific self-efficacy for people with mild to moderate chronic kidney disease (stages 1 to 3). The tool was developed in English for content validity testing and translated into Chinese to conduct evaluation of reliability and construct validity (Lin et al., 2012). Instrument reliability was evaluated with a nonrandom sample of 594 subjects with stage 2 and 3 chronic kidney disease, aged 23 to 86 years (Streiner & Norman, 2009). Subjects were recruited from three medical facilities in Taiwan. Cronbach's alpha demonstrated strong internal consistency ($a = 0.94$) for the entire scale. This coefficient may indicate redundancy of items. The CKD-SE instrument demonstrated acceptable stability (n = 26) when re-administered 2 weeks apart (r= 0.72, p<0.001) (Lin et al., 2012; Streiner & Norman, 2008).

Content validity testing included the development and judgment phases. The first author of the CKD-SE tool also designed and tested the DSMI. Findings from the literature review and qualitative research for the DSMI were used to generate the attributes and items of the CKD-SE instrument. A panel of eight experts including nephrologists, dietitians and nurses were consulted. The content validity index was high (0.89) (Lin et al., 2012; Lynn, 1986).

Four attributes were identified for the CKD-SE; the first ‘autonomy’ was described as the patients’ confidence with asking questions or raising concerns to health care providers (Lin et al., 2012; Lorig & Holman, 2003). The second ‘self-integration’ was defined as patients’ confidence to modify their lifestyle in a way that incorporates the treatment regimens while maintaining an overall balanced life (Denyes et al., 2001; Lin et al., 2012; Orem, 1985). The third ‘problem solving’ was the patients’ confidence to learn disease-specific information that aided in illness management (Lin et al., 2012; Lorig & Holman, 2003). The last attribute was ‘seeking social support’ which involves the patients’ confidence to ask for help from friends or family to cope with the illness (Denyes et al., 2001; Lin et al., 2012; Lorig & Holman, 2003). The rationale for modifying the dissertation work on the DSMI and mixing the concept of self-efficacy (‘confidence’) with self-management was not clear (Lin et al., 2012). Though Lorig described self-efficacy as a component of self-management, it was differentiated from the other attributes (Lorig & Holman, 2003). Removal of the term confidence from the above definitions would generate congruence between the attributes of the instrument and self-management and self-care theory. Construct validity, predictive validity, discriminatory ability, and readability have not been completed for the CKD-SE (Lin, 2005; Lin et al., 2012).

End Stage Renal Disease Adherence Questionnaire (ESRD-AQ)

The ESRD-AQ is a 46-item tool designed to measure the adherence behaviors, knowledge and treatment perceptions of patients receiving in-center hemodialysis (Kim et al., 2010). Higher scores represent better adherence. The tool was developed and tested using a homogeneous sample of 58 in-center hemodialysis patients from eight facilities in Los Angeles. Subjects had received hemodialysis therapy for three months to 24 years and ranged in age from 21 to 83 years (Streiner & Norman, 2009). The primary cause of renal failure was hypertension and diabetes mellitus (Kim et al., 2010).

The evaluation of internal consistency was omitted, as Kim et al (2010) stated that the tool does not contain homogeneous items. Adherence is a narrow construct that describes the obedience of the patient when following medical recommendations (Chan et al., 2010). As such, some degree of homogeneity should be achievable. Further testing the internal consistency provides an indication of the scope of the instrument (Streiner & Norman, 2008). Without this information one is unable to determine whether the items adequately capture the construct of adherence (Butt, 2006; Streiner & Norman, 2008; Waltz, Strickland & Lenz, 2005). The response format for the ESRD-AQ used a combination of Likert scales, yes/no and multiple-choice answers making the calculation of correlation coefficients complicated. Regardless the authors of the tool should have attempted to quantitatively evaluate the internal consistency of the ESRD-AQ. Stability measures were examined by randomizing 10% of the sample (n = 6) and re-administering the tool two days after initial testing. The ICC ranged from 0.83 to 1.0 indicating acceptable test-retest reliability of the ESRD-AQ. It is important to note that the ICC was based on 14 of the 58 items as not all tool items were scoreable due to the mixture of response formats (Kim et al., 2010; Streiner & Norman, 2008).

Content validity involved the development and judgment phases of testing. An extensive literature review was used to determine attributes associated with adherence.

Seven experts comprised of nephrologists, nurses, dietitians and a nurse practitioner evaluated the tool. The overall content validity index for the ESRD-AQ was 0.99 (Kim et al., 2010; Lynn, 1986).

Analysis of construct validity indicated that the attributes of the ESRD-AQ were inconsistent with self-management theory. This is not surprising given that the instrument was designed to measure adherence behaviors and patients' knowledge and treatment perceptions (Kim et al., 2010). Kim et al. (2010) identified the following components; hemodialysis attendance, fluid restrictions, medication use, and diet recommendations. Criterion validity was conducted by dividing the sample into two groups comprised of adherers and non-adherers based on clinical guidelines ('gold' standard) for maintenance hemodialysis. For example, serum potassium levels should be between 3.5 to 4.5 mmol/L. Subjects within this range were labeled adherent, those outside this range non-adherent. The Mann-Whitney U test was utilized to compare mean scores between those identified as adherers and non-adherers with responses to items on the instrument. Results were statistically significant for adherence related questions and no differences were evident for knowledge and perception related questions. Kim et al (2010) did not evaluate the predictive validity, discriminatory ability and practical properties of the ESRD-AQ (Butt, 2006; Kim et al., 2010; Streiner & Norman, 2008).

Discussion

Implications for Nursing Research, Policy and Practice

This critical analysis was challenging owing to considerable variation of psychometric findings of the tools. Evaluation of the SCHFI and EHFScB scale demonstrated parameters acceptable for application in nursing research to measure the self-care of adults diagnosed with heart failure (Jaarsma et al., 2009; Jaarsma et al., 2003; Riegel et al., 2000; Riegel et al., 2004; Streiner & Norman, 2008). The SCHFI was congruent with components of Lorig's self-management theory (Lorig & Holman, 2003; Lorig et al., 1999) and the EHFScB scale with Orem's self-care theory (Orem, 1985; Orem, 1995). However, each instrument focused on different attributes of self-care and self-management (Shuldham et al., 2007). The diversity of attributes was likely owing to the lack of conceptual clarity regarding self-management and self-care (Embrey, 2006; Hughes, 2010). Amalgamating the two instruments may improve the comprehensiveness of attributes that comprise the tool. Items from the SCHFI and EHFScB scale could be combined to create one cohesive instrument followed by psychometric evaluation. Utilization of one tool would produce comparative data across nursing studies. Assessment of predictive validity and discriminatory ability on the English versions of these instruments has not been completed (Butt, 2006; Streiner & Norman, 2008).

The SDSCA scale was designed to measure the self-care activities of adults with type I and type II diabetes. Close examination of construct validity revealed that the tool actually measured adherence behaviors (Toobert & Glasgow, 1994). The SDSCA scale was developed in the 1980s, when emphasis on adherence was more prevalent than broader conceptualizations of self-management (Costantini, 2006). Further inconsistent psychometric data suggests the tool requires revision and should not be used for research or in clinical practice settings (Toobert & Glasgow, 1994; Toobert et al., 2000; Streiner & Norman, 2008).

The DSMI measures the self-management of adults with type II diabetes. Preliminary results suggest the DSMI is appropriate for research and application in clinical practice. Internal consistency indicated that redundancy of items and revision is required. The tool included attributes of self-management and self-care and captures the multidimensional aspects of this construct (Lin, 2005). Interestingly, a moderately strong correlation between the SDSCA scale and DSMI was evident which may suggest that self-management and adherence are correlated (Lin, 2005; Streiner & Norman, 2008). Patients must inevitably follow some sort of treatment regime when diagnosed with diabetes or other vascular conditions (Lorig & Holman, 2003). Debate regarding the attributes of adherence is beyond the scope of this paper.

The CKD-SE and ESRD-AQ violated the inclusion and exclusion criteria for this analysis however, other tools that measured self-management of kidney disease for adults were not found in the literature. The CKD-SE tool was designed to measure disease-specific self-efficacy for patients with mild to moderate chronic kidney disease. The tool should not be used for nursing research or clinical practice as it has undergone reliability and content validity testing only. Construct and predictive validity and discriminatory ability are necessary before any recommendations for its application can be made (Lin et al., 2012; Streiner & Norman, 2008). As well, the attributes of the CKD-SE were confusing. The author used qualitative data on self-management to generate items related to self-efficacy. Though these concepts may be related, combining both for the purposes of measurement may not be appropriate. Clarification is needed regarding which attributes are consistent with self-management and those representative of self-efficacy

(Lin, 2005; Lin et al., 2012). The ESRD-AQ was developed to measure adherence for adults requiring hemodialysis therapy. The tool is not ready for application in research or clinical practice. The ESRD-AQ requires extensive revision to modify the inconsistent response format and inability to score several items on the tool. Further psychometric testing is necessary to evaluate the reliability, construct validity, predictive validity and discriminatory ability (Kim et al., 2010; Streiner & Norman, 2008).

With the exception of the Spanish version of the EHFScB scale (Gonzalez et al., 2006), psychometric information on predictive validity and discriminatory ability was not found in the literature for the instruments analyzed here. Predictive validity may be challenging to evaluate when measuring self-management (Streiner & Norman, 2008; Waltz et al., 2005). Behaviors and ability to self-manage fluctuate over longer time owing to changes in motivation, social support networks, and illness severity leading to loss of independence Audulv, 2013; Lorig et al., 1999). More research is needed before nurses can use these instruments to determine future outcomes (Streiner & Norman, 2008).

Discriminatory ability is assessed by comparing groups known to have the trait with those that do not (Butt, 2006; Streiner & Norman, 2008). For example, the Functional Outcomes Sleep questionnaire measures the impact of excessive sleepiness on activities of daily living. To evaluate discriminatory ability, instrument scores of subject’s known to have a sleep disorder were compared with those that do not and significant differences were evident indicating the tool distinguishes between high and low scorers (Weaver et al., 1997). Differentiating groups of patients based on self-management is difficult which may explain the omission of discriminatory ability from psychometric assessment of the tools. Despite the complexity nurses should not avoid this evaluative component. For tools designed to measure the self-management of patients requiring hemodialysis, comparing those utilizing home based therapies with in-center patients may provide evidence for the discriminatory ability of the instrument. Patients who dialyze at home must independently perform their own treatments and should produce higher self-management scores (Loos-Ayav et al., 2008; Streiner & Norman, 2008). This may be one approach to assess the discriminatory ability of self-management instruments for patients with vascular conditions requiring hemodialysis (Butt, 2006; Streiner & Norman, 2008).

Quantification of self-management is critical to effectively evaluate nursing practices and policies. Studies that use other parameters such as quality of life, hospitalization rates and health care costs suggest that services aimed at improving self-management are effective (Boyde, et al., 2011; Chan et al., 2010; Chen et al., 2009; Powers et al., 2009; Su et al., 2009). However, this data does not provide evidence to determine which components of nursing practice and interventions best fit patient specific needs. Accurate measurement that reflects the conceptual attributes of self-management may provide data regarding the patient’s ability to self-manage and services required (Bayliss et al., 2007; Blickem et al., 2011; Dodd & Dibble, 1993). For example, patients diagnosed with diabetes and hypertension receiving dialysis report several barriers for home-based therapies (Cefazzo et al., 2009; McLaughlin et al., 2003; Oliver et al., 2010). A self-management tool for adults with vascular disease may help to highlight deficits that could be addressed with tailored interventions designed to support specific areas of concern.

Conceptual clarity of self-management and self-care is fundamentally important prior to instrument development. Given the considerable focus on self-management, nurses need reliable and validated tools to measure outcomes. Accurate quantitative evidence is essential to produce rigorous research findings to garner support for policy changes and practice interventions. Future studies are required to develop and psychometrically evaluate global self-management instruments for adults with vascular conditions.

References

Audulv, A. (2013). The over time development of chronic illness self-management patterns: A longitudinal qualitative study. *BMC Public Health,13*, 452. doi: 10.1186/1471-2458-13-452.

Bayliss, E. A., Bosworth, H. B., Noel, P. H., Wolff, J. L., Damush, T. M., & Mciver, L. (2007). Supporting self-management for patients with complex medical needs: Recommendations of a working group. *Chronic Illness, 3*, 167-175. doi: 10.1177/1742395307081501

Blickem, C., Bower, P., Protheroe, J., Kennedy, A., Vassilev, I., Sanders, C…Rogers, A. (2011). The role of information in supporting self-care in vascular conditions: A conceptual and empirical review. *Health and Social Care in the Community, 19*(5), 449-459.

Boyde, M., Turner, C., Thompson, D. R., & Stewart, S. (2011). Educational interventions for patients with heart failure: A systematic review of randomized controlled trials. *Journal of Cardiovascular Nursing, 26*(4), E27-35.

Butt, M. (2006). *PhD Thesis: Chapter 4 – Measurement*. Hamilton, ON: McMaster University.

Cafazzo, J. A., Leonard, K., Easty, A. C., Rossos, P. G., & Chan, C. T. (2009). Patient-perceived barriers to the adoption of nocturnal home hemodialysis. *Clinical Journal of Society of Nephrology, 4*, 784-789. doi: 10.2215/CJN.05501008

Canadian Organ Replacement Register (2011). *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2000-2009.*

Retrieved from http://secure.cihi.ca/cihiweb/products/2011_CORR_Annual_Report_final_e.pdf.

Cardiac Care Network of Ontario (2012). *Shaping the future of vascular health: An integrated vascular health blueprint for Ontario*. Retrieved from http://www.opha.on.ca/Integrated% 20Vascular%20Health%20Blueprint%20for%20Ontario_August%202012.pdf.

Case Western Reserve University (2009). *Center for excellence for self-management advancement through research and translation*. Retrieved from http://fpb.case.edu/SMARTCenter/selfmgmt.shtm

Chan, M. F., Wong, F. K. Y., & Chow, S. K. Y. (2010). Investigating the health profile of patients with end-stage renal failure receiving peritoneal dialysis: A cluster analysis. *Journal of Clinical Nursing, 19*(5-6), 649-657. doi: http://dx.doi.org/10.1111/j.1365-2702.2009.03103.x

Chen, S. L., Tsai, J. C., & Lee, W. L. (2009). The impact of illness perception on adherence to therapeutic regimens of patients with hypertension in Taiwan. *Journal of Clinical Nursing, 18*(15), 2234-2244.

Choi, E. J., Nam, M., Kim, S. H., Park, C. G., Toobert, D. J., Yoo, J. S., & Chu, S. H. (2011). Psychometric properties of a Korean version of the summary of diabetes self-care activities measure. *Internal Journal of Nursing Studies, 48*, 333-337.

Costantini, L. (2006). Compliance, adherence and self-management: Is a paradigm shift possible for chronic kidney disease clients? *Canadian Association of Nephrology Nurses and Technologists Journal, 16*(4), 22-26.

Costantini, L., Beanlands, H., & Horsburgh, M. (2011). Development of the self-care for Adults on dialysis tool (SCAD). *CANNT Journal, 21*(2), 38-43.

Denyes, M. J., Orem, D. E., & SozWiss, G. B. (2001). Self-care: A foundational science. *Nursing Science Quarterly, 14*(1), 48-54.

DeVellis, R. F. (2012). *Scale development: Theory and applications*. (3rd Ed.) California, United States of America: Sage Publications.

Dodd, M. J., & Dibble, S. L. (1993). Predictors of self-care: A test of Orem's model. *Oncology Nursing Forum, 20,* 895-901.

Du, H. Y., Newton, P. J., Zecchin, R., Denniss, R., Salamonson, Y., Everett, B., Currow, D. C., Macdonald, P. S., & Davidson, P. M. (2011). An intervention to promote physical activity and self-management in people with stable chronic heart failure the home-heart-walk study: Study protocol for a randomized controlled trial. *Trials, 12,* 63. doi: http://dx.doi.org/10.1186/1745-6215-12-63.

Embrey, N. (2006). A concept analysis of self-management in long-term conditions. *British Journal of Neuroscience Nursing, 2*(10), 507-513.

Funnell, M. M., Brown, T. L., Childs, B. P., Haas, L. B., Hosey, G. M., Jensen, B., …Weiss, M. A. (2008). National standards of diabetes self-management education. *Diabetes Care, 31*, Suppl 1, S97-S104. doi: 10.2337/dc0-S097

Gonzalez, B., Lupon, L., Parajon, T., Urrutia, A., Hurreros, J. & Valle, V. (2006). Use of the European Heart Failure Self-care Behaviour Scale (EHFScBS) in a heart failure unit in Spain. [Abstract]. *Revista Espanola de Cardiologia, 59,* 166.

Hughes, L. (2010). *Chronic disease self-management: An evolutionary concept analysis.*

Retrieved http://dspace.library.uvic.ca:8080/bitstream/handle/1828/4057/Hughes_Lori_MN_2010.pdf?sequence=1.

Jaarsma, T., Arestedt, K. F., Martensson, J., Dracup, K., & Stromberg, A. (2009). The European Heart Failure Self-care Behavior scale revised into a nine-item scale (EHFScB-9): A reliable and valid international instrument. *European Journal of Heart Failure, 11*, 99-105.

Jaarsma, T., Stromberg, A., Martensson, J., & Dracup, K. (2003). Development and testing of the European Heart Failure Self-Care Behaviour Scale. *The European Journal of Heart Failure, 5*, 363-370.

Kim, Y., Evangelista, L. S., Phillips, L. R., Pavlish, C., & Kopple, J. D. (2010). The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ): Testing the psychometric properties in patients receiving in-center hemodialysis. *Nephrology Nursing Journal, 37*(4), 377-393.

Lin, C. C. (2005). *Development and testing of the diabetes self-management instrument*. Unpublished doctoral dissertation, The University of Michigan.

Lin, C. C., Anderson, R. M., Chang, C. S., Hagerty, B. M., & Loveland-Cherry, C. J. (2008). Development and testing of the Diabetes Self-Management Instrument: A confirmatory analysis. *Research in Nursing & Health, 31*, 370-380.

Lin, A., Cavendish, T., Boren, D., Ofstad, T., & Seidensticker, D. (2008). A pilot study: Reports of benefits from a 6-month, multidisciplinary, shared medical appointment approach for heart failure patients. *Military Medicine, 173*, 1210-1213.

Lin, C. C., Wu, C. C., Anderson, R. M., Chang, C. S., Chang, S. C., Hwang, S. J., & Chen, H. C. (2012). The chronic kidney disease self-efficacy (CKD-SE) instrument: Development and psychometric evaluation. *Nephrology Dialysis Transplantation, 27*, 3828-3834.

Loos-Ayav, C., Frimat, L., Kessler, M., Chanliau, J., Durand, P., & Briancon, S. (2008). Changes in health-related quality of life in patients of self-care vs. in-center dialysis during the first year. *Quality of Life Research, 17*(1), 1-9. doi: http://dx.doi.org/10.1007/s11136-007-9286-1

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definitions, outcomes, and mechanisms. *Annals in Behavioral Medicine, 26*(1), 1-7.

Lorig, K. R., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice*, *4*(6), 256-262.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Ritter, P. L., Gonzalez, V. M. … Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing utilization and costs: A randomized trial. *Medical Care, 37*(1), 5-14.

Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research, 35*(6), 382-386.

McLaughlin, K., Manns, B., Mortis, G., Hons, R., & Taub, K. (2003). Why patients with ESRD do not select self-care dialysis as a treatment option. *American Journal of Kidney Diseases, 41*(2), 380-385.

Oliver, M. J., Garg, A. X., Blake, P.G., Johnson, J. F., Verrelli, M., Zacharias, J. M. … Quinn, R. R. (2010). Impact of contraindications, barriers to self-care and support on incident peritoneal dialysis utilization. *Nephrology Dialysis Transplantation, 25,* 2737-2744. doi: 10.1093/ndt/gfq085

Orem, D. E. (1985). A concept of self-care for the rehabilitation client. *Rehabilitation Nursing Journal*, *10*(3), 33-6.

Orem, D. E. (1995). *Nursing: Concepts of practice*. (5th Ed.) St. Louis, United States of America: Mosby-Year Book.

Orem, D. E. & Vardiman, E. M. (1995). Orem's nursing theory and positive mental health: Practical considerations. *Nursing Science Quarterly, 8*(4), 165-173.

Powers, B. J., Olsen, M. K., Oddone, E. Z., & Bosworth, H. B. (2009). The effect of a hypertension self-management intervention on diabetes and cholesterol control. *American Journal of Medicine, 122*(7), 639-646. doi: http://doi.org/10.1016/ j.amjmed.2008112.022.

Riegel, B., Carlson, B., & Glaser, D. (2000). Development and testing of a clinical tool measuring self-management of heart failure. *Heart & Lung, 29*(1), 4-12.

Riegel, B., Carlson, B., Moser, D. K., Sebern, M., Hicks, F. D., & Roland, V. (2004). Psychometric testing of the self-care of heart failure index. *Journal of Cardiac Failure, 10*(4), 350-360.

Riegel, B., Lee, C. S., Dickson, V. V., & Carlson, B. (2009). An update on the self-care of heart failure index. *Journal of Cardiovascular Nursing, 24*(6), 485-497.

Rothenberger, C. D. (2011). Chronic illness self-management in prediabetes: A concept analysis. *Journal of Nursing and Healthcare of Chronic Illness: An International Journal, 3*, 77-86.doi:10.1111/j.1752-9824.2011.01092.x

Scollan-Koliopoulos, M., & Walker, E. A. (2009). Multigenerational timeline and understanding of diabetes and self-care. *Research and Theory for Nursing Practice, 23*(1), 62-77.

Shuldham, C., Theaker, C., Jaarsma, T., & Cowie, M. (2007). Evaluation of the European heart failure self-care behaviour scale in a United Kingdom population. *Journal of Advanced Nursing, 60*, 87-95.

Streiner, D. L., & Norman, G. R. (2008). *Health Measurement Scales: A Practical Guide to their Development and Use*. New York, NY: Oxford University Press.

Streiner, D. L., & Norman, G. R. (2009). *PDQ: Pretty Darned Quick Epidemiology* (3rd Ed.). Shelton, Connecticut: People's Medical Publishing House.

Su, C., Lu, X., Chen, W., & Wang, T. (2009). Promoting self-management improves the health status of patients having peritoneal dialysis. *Journal of Advanced Nursing, 65*(7), 1381-1398. doi: http://dx.doi.org/10.1111/j.1365-2648.2009.04993.x

Toobert, D. J., & Glasgow, R. E. (1994). *Assessing diabetes self-management: Summary of Diabetes Self-Care Activities Questionnaire*. In C. Bradley (Ed.), Handbook of psychology and diabetes (pp. 351-375). Langhorne, PA: Harwood Academic Publishers.

Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The summary of diabetes self-care activities measure. *Diabetes Care, 23*, 943-950.

Vincent, D. McEwen, M. M., & Pasvogel, A. (2008). The validity and reliability of a

Spanish version of the summary of diabetes self-care activities questionnaire. *Nursing Research, 57*(2), 101-106.

Visaya, M. A. (2010). Hemodialysis patients' perceptions of home hemodialysis and self-care. *CANNT Journal*, *20*(2), 23-28.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2005). *Measurement in Nursing and Health Research*. New York, NY: Springer Publishing Company.

Wangberg, S. C. (2008). An internet-based diabetes self-care intervention tailored to self-efficacy. *Health Education Research, 23*(1), 170-179. doi: 10.1093/her/cym014

Weaver, T. E., Laizner, A. M., Evans, L. K., Maislin, G., Chugh, D. K., Lyon, K., …Dinges, D. F. (1997). An instrument to measure functional status outcome for disorders of excessive sleepiness. *Sleep, 20*(10), 835-843.

Weinger, K., Butler, H. A., Welch, G. W., & La Greca, A. M. (2005). Measuring diabetes self-care: A psychometric analysis of the Self-care Inventory-revised with adults. *Diabetes Care, 28*(6), 1346-1352.

Appendix A – Response format for Critical Analysis Matrix using Streiner & Norman (2008)

The table below explicates how responses were provided in the matrix. The findings are reported in Appendix B.

Critical Analysis Indictors for tools reviewed	*Response Format*
Reliability	
How were sampling procedures conducted?	For each instrument the sampling procedures used to conduct reliability testing are identified. For example, random, nonrandom and convenience.
Was a homogeneous or heterogeneous sample tested?	The term homogeneous or heterogeneous appears in the box as appropriate.
Is the internal consistency (Cronbach's alpha a) weak, moderate or strong?	Good = 0.70, commendable = 0.80, strong = 0.90
Are stability measures acceptable or unacceptable? (Test-retest)	Acceptable ^{3} 0.70, Unacceptable < 0.70 The coefficients of each instrument are also reported.
Content Validity	
What was the stated purpose of the tool?	Measure self-management (SM) = the purpose of the tool was the measurement of self-management (SM) or self-care (SC) Other = the purpose was to measure a concept other than self-management
Was content validity testing conducted?	Yes/no Yes, indicates that one or both phases (development and/or judgment) of content validity testing were conducted. A no response means that content validity testing was not conducted.
Was content validity testing conducted with a panel of experts?	Yes/no If yes, number (n) of experts consulted was reported.
Construct Validity	
What attributes were identified?	A brief synopsis of the attributes associated with the self-management instruments are identified.
Are the attributes consistent with theories of self-management and/or self-care?	Yes/no Yes, the attributes are congruous with self-care and/or self-management theories or no they are not.

How was validation testing conducted? (**Criterion, convergent, divergent, concurrent**)	The term criterion, convergent or concurrent appears in the box as appropriate.
Was the tool compared with another similar tool?	Yes/no Yes, it was compared with another tool. If yes, which tool. No it was not compared with another tool.
How strong was the correlation between the tools?	If completed the correlation and statistical significance was reported. Strong = 0.70 to 0.90, moderate = 0.40 to 0.60, weak = 0.1 to 0.3
Predictive Validity	
Does the tool actually predict the intended outcome?	Yes/no, or not completed Yes, the tool does have predictive validity or no it did not. Not completed indicates this data was not found in the literature.
Discriminatory Ability	
Does the tool differentiate between low versus high scorers?	Yes/no or not completed Yes, the tool does demonstrate discriminatory ability or do it does not. Not completed indicates this data was not found in the literature.
Practical Properties	
How many items are in each tool?	Provides information on the number of items in each instrument.
How many minutes is required to complete the tool?	Gives an approximation of the number of minutes required to complete the tool.
Was readability evaluated?	Reports information on the literacy level required to complete the tool.

Appendix B – Results of the Critical Analysis Matrix using Streiner & Norman (2008)

Critical Analysis Indictors for tools reviewed	**Self-Care of Heart Failure Index**	**European Heart Failure Self-Care Behaviour Scale**	**Summary of Diabetes Self-care Activities Scale**	**Diabetes Self-Management Instrument**
Reliability				
How were sampling procedures conducted?	Convenience	Convenience	Random and nonrandom	Nonrandom
Was a homogeneous or heterogeneous sample tested?	Homogeneous	Heterogeneous	Heterogeneous	Homogeneous
Is the internal consistency (Cronbach's alpha a) weak, moderate or strong?	Good $a = 0.76$	Good $a = 0.77$	Weak Mean inter-item correlation=0.47	Strong $a = 0.94$
Are stability measures acceptable or unacceptable? (Test-retest)	Not completed	Acceptable Bland-Altman plot (-0.5)	Not acceptable to acceptable r=-0.05 to 0.78 $p<0.01$ to 0.001	Acceptable $r = 0.73$ $p<0.001$
Content Validity				
What was the stated purpose of the tool?	Measure SC	Measure SC	Other	Measure SM
Was content validity testing conducted?	Yes	Yes	Yes	Yes
Was content validity testing conducted with a panel of experts?	No	Yes, n = 10 CVI[5] = not reported	Yes, n = not reported Delphi method	Y, n = 7 CVI[5] = 0.90
Construct Validity				
What attributes were identified?	Decision-making, problem solving, symptom monitoring, treatment implementation, evaluation and self-confidence	Attending to treatment regime, seeking assistance from health care providers and lifestyle modification	Adherence to diabetes treatment regimes	Self-regulation, Self-integration, interactions with health providers and significant others, prevention and therapeutic related activities
Are the attributes consistent with theories of self-management and/or self-care?	Yes	Yes	No	Yes

CVI[5] = Content validity index

Appendix B – Results of the Critical Analysis Matrix using Streiner & Norman (2008) – continued

Critical Analysis Indictors for tools reviewed	**Self-Care of Heart Failure Index**	**European Heart Failure Self-Care Behaviour Scale**	**Summary of Diabetes Self-care Activities Scale**	**Diabetes Self-Management Instrument**
How was validation testing conducted? (**Criterion, convergent, divergent, concurrent**)	Criterion (also referred to as known-group validity)	Convergent (using HFCQ[1]), divergent (MLwHFQ[2]), concurrent (SCHFI[3])	Concurrent (several different scales), criterion (glycosated hemoglobin)	Convergent (SDSCA[4]), (gylcosated hemoglobin and Diabetes Empowerment scale)
Was the tool compared with another similar tool?	No	Yes HFCQ[1] , MLwHFQ[2] , SCHFI[3]	Yes – several different scales	Yes SDSCA[4]
How strong was the correlation between the tools?	Not applicable	Weak HFCQ[1] $r = 0.32, p<0.001$ MLwHFQ[2] $r = 0.01, p<0.001$ SCHFI[3] $r=0.09$, $p=0.25$	Weak to moderate $r=-0.23$ to 0.58 $p<0.01, p<0.05, p<0.001$	Moderate $r = 0.55$ $p < 0.001$
Predictive Validity				
Does the tool actually predict the intended outcome?	Not completed	Yes	Not completed	Not completed
Discriminatory Ability				
Does the tool differentiate between low versus high scorers?	Not completed	Not completed	Not completed	Not completed
Practical Properties				
How many items are in each tool?	15-items	12-items	25-items	35-items
How many minutes is required to complete the tool?	5 minutes	5 to 10 minutes	5 to 10 minutes	Not reported
Was readability evaluated?	No	No	No	No

[1] HFCQ = Heart Failure Compliance Questionnaire

[2] MLwHFQ = Minnesota Living with Heart Failure Questionnaire

[3] SCHFI = Self-care Heart Failure Index

[4] SDSCA = Summary of Diabetes Self-Care Activities scale

Appendix B – Results of the Critical Analysis Matrix using Streiner & Norman (2008) – continued

Critical Analysis Indictors for tools reviewed	**Chronic Kidney Disease Self-Efficacy Instrument**	**End Stage Renal Disease Adherence Questionnaire**
Reliability		
How were sampling procedures conducted?	Non-random	Non-random
Was a homogeneous or heterogeneous sample tested?	Homogeneous	Homogeneous
Is the internal consistency (Cronbach's alpha a) weak, moderate or strong?	Strong $a = 0.94$	Not completed
Are stability measures acceptable or unacceptable? (Test-retest)	Acceptable r =0.72, p<0.001	Acceptable ICC[1] = 0.83 to 1.0
Content Validity		
What was the stated purpose of the tool?	Other	Other
Was content validity testing conducted?	Y	Y
Was content validity testing conducted with a panel of experts?	Y, n = 8 CVI = 0.89	Y, n = 7 CVI = 0.99
Construct Validity		
What attributes were identified?	Autonomy, self-integration, problem solving, social support	HD attendance, medication use, fluid restrictions and diet recommendations
Are the attributes consistent with theories of self-management and/or self-care?	Yes, if self-efficacy (confidence) removed	No
How was validation testing conducted? (**Criterion, convergent, divergent, concurrent**)	Not completed	Criterion
Was the tool compared with another similar tool?	No	No
How strong was the correlation between the tools?	Not applicable	Not applicable
Predictive Validity		
Does the tool actually predict the intended outcome?	Not completed	Not completed
Discriminatory Ability		
Does the tool differentiate between low versus high scorers?	Not completed	Not completed
Practical Properties		
How many items are in each tool?	25-items	46-items
How many minutes is required to complete the tool?	15 to 25 minutes	20 to 40 minutes
Was readability evaluated?	No	No

[1] ICC = Intraclass correlation coefficient CVI[5] = Content validity index

Appendix C – New York Heart Association (NYHA) classification of heart failure

Class	Functional Capacity
I	Patients with cardiac disease but resulting in no limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea or anginal pain.
II	Patients with cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea or anginal pain.
III	Patients with cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea or anginal pain.
IV	Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort increases.

Class	Objective Assessment
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

American Heart Association (2013). *Classes of Heart Failure.* Retrieved from http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp

Appendix B: Conceptualization of self-management for adults with chronic kidney disease

McMaster University
Nursing Graduate Program
PhD Comprehensive Examination

Area A:
Practice and Specialization-Related Issue

Conceptualization of self-management for adults with chronic kidney disease

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12 September 2013

Introduction

Self-management has garnered considerable attention within the chronic illness literature. A chronic illness that poses tremendous burden on the health care system and society is chronic kidney disease. In Canada, 1 in 10 are diagnosed with kidney disease and the number of patients with end stage renal failure has tripled over the last 20 years. For those receiving dialysis treatment the average cost to the health care system is $70, 000 per patient year (Kidney Foundation of Canada, 2013). The alarming rise in the prevalence of chronic kidney disease is precipitated by diabetes and hypertension. Collectively these chronic illnesses are referred to as vascular diseases. The presence of more than one vascular condition adds greater complexity for health care professionals striving to develop self-management interventions (Canadian Organ Replacement Register [CORR], 2011; Heart and Stroke Foundation, 2010).

Nurse-led initiatives in collaboration with other health care professionals (physicians, pharmacists, dietitians) can effectively promote self-management (Jessee, Thomas & Rutledge, 2012; Molzahn et al., 2008; Morgan, Dunbar, Reddy, Coates & Leahy, 2009; Tshiananga et al., 2012; Watts et al., 2009). Despite the abundance of literature, there is a lack of consistency regarding the dimensions of self-management in relation to adults with vascular diseases. This ambiguity makes comparative analysis of research findings difficult to impossible generating further variations of nursing practice and policies. Reports demonstrate that only 18% of individuals with a chronic illness were given written instructions on how to manage their disease (Lavis & Boyko, 2009). Provincial goals aimed at improving self-management within the dialysis population have fallen well short of targets (CORR, 2011; Visaya, 2010). These findings suggest that the conceptualization of self-management influences nursing practice, policy and research. Due to the vast literature on vascular diseases, this analysis must be limited to the self-management of chronic kidney disease.

The Walker and Avant (2011) method was used to conduct the concept analysis. The framework consists of the following steps: 1) identify the purpose of the analysis 2) determine all uses of the concept 3) determine the defining attributes 4) identify a model case 5) identify borderline, related, contrary, invented and illegitimate cases 6) identify the antecedents and consequences and 7) delineation of empirical referents (Walker & Avant, 2011). The analysis is followed by a discussion of the strengths and limitations of the concept analysis, implications for nursing practice, policy and research and recommendations for future concept development.

Methods

Search Strategy

An extensive literature search was conducted using a variety of strategies to locate pertinent publications. Specifically, Medline, Embase, PsychINFO, HealthStar, CINAHL, Sociological Abstracts and Google Scholar databases provided comprehensive access to the literature from 1980 to 2012. The McMaster University librarian was consulted to determine which search terms would best facilitate robust literature extraction. The following keywords: self-care, self-manage, self-regulate, self-monitor, chronic kidney disease, kidney disease, renal insufficiency, end stage renal disease, concept, models and frameworks were combined and exploded. Articles that focused on chronic kidney disease and contained the word self-management, self-care management or self-care in the title or abstract were included in the concept analysis. The reference lists of relevant publications were examined for additional articles. The search strategy was limited to articles published in English. Articles examining children, adolescent or family caregivers were excluded.

Data Selection

Walker and Avant (2011) do not provide clear guidelines regarding methodology of data selection and extraction. The approach described below was developed based on experiential knowledge and practice with extension literature reviews. Several documents were found including theoretical articles, research publications, books and organization websites (Table 1). The abundance of literature necessitated a twofold approach for data selection and analysis. In phase one, all publications were reviewed in their entirety and content relevant to self-management was highlighted. Direct quotes were transcribed into tables with the respective references. The first phase of data selection generated 72 documents. The information was used to complete the following steps: a) identify all uses, b) model case, c) borderline, related, contrary, invented, and illegitimate cases and d) define empirical referents from Walker and Avant (2011). This process generated the largest possible number of sources to reduce bias (Walker & Avant, 2011).

For phase two, data from the tables produced in phase one were scrutinized and the origin of each quote was examined. Articles that repeated the seminal writings of others without adding any new insights to the concept of self-management were eliminated. For example, the publications of Orem (1985) and Lorig and colleagues (2003, 1999) were frequently cited in numerous research articles. These studies focused on clinical markers as opposed to the concept of self-management. The second phase resulted in a subsample of 27 articles which was applied to steps: a) define attributes and b) identification of antecedents and consequences from Walker and Avant (2011). The smaller sample supported greater depth of analysis of self-management for adults with chronic kidney disease (Walker & Avant, 2011).

Findings

The first step of the Walker and Avant (2011) method was determining the purpose of the concept analysis. The aims were to examine the range of meanings associated with self-management and to lend clarity to the dimensions ascribed to the self-management of chronic kidney disease.

Identifying uses of self-management

The second step in the concept analysis was to identify all uses of self-management. According to the Oxford dictionary (2013a) self-management is “the taking of responsibility for one’s own behavior and well-being” and “the distribution of political control to individual regions of a state, especially as a form of socialism practiced by its own members.” It is clear that self-management involves acting autonomously to enhance one’s health or environment.

The focus of this concept analysis was the self-management of chronic kidney disease, therefore the definitions and usage specific to these areas was explored. Lorig & Holman (2003) stated that self-management of chronic illness is “a lifelong task aimed at maintaining wellness” (p.1) and includes five core skills “problem solving, decision-making, resource utilization, forming of patient/health care provider partnership, and taking action" (p. 2) The Registered Nurses Association of Ontario (RNAO, 2010) best practice guideline on self-management of chronic illness cited the following definition "... the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions" (p. 17). Gruman and Von Korff (1996) have proposed that self-management "involves patients' engagement in activities that protect and promote health; their observation of symptoms and signs of illness; their adherence to treatment regimens; and their management of the effects of illness on functioning, emotions, and interpersonal relationships" (p.1). The active participation in tasks that promote health and partnering with health care professionals to manage the illness was a recurrent idea across definitions. However, resources, self-efficacy, adherence and attending to the stressors of everyday life were inconsistent. The conflicting views on self-management of chronic illness may contribute to its association with other concepts.

Examination of additional sources revealed explicit statements that self-management is the amalgamation of numerous concepts including "self-care, adherence, compliance, health behavior change, patient education, and collaborative care" (Case Western Reserve University, 2009). A discussion of all these concepts is beyond the scope of this paper. However, extensive literature review indicated that self-management and self-care were often used interchangeably (Curtin & Mapes, 2001; Lorig & Holman, 2003; Orem, 1985; Orem & Vardiman, 1995). A brief review of self-care is warranted. According to the Oxford dictionary (2013b) self-care is "care for oneself". The concept of self-care originated in the 1960s (Orem, 1985). Orem (1980) described self-care as a learned "set of actions performed within the context of day to day living that maintain their health and ameliorate disease". The World Health Organization (WHO, 1983) stated that self-care is "the activities undertaken to enhance health and prevent disease in collaboration with health care professionals" (p. 2). Consistent here are active participation and partnering with health care professionals. Orem (1980, 1985) highlights the need to incorporate self-care into daily life whereas the WHO (1983) does not. Though incongruences are apparent, several similarities between self-management and self-care are evident. Both concepts describe the active engagement in tasks that improve health, collaboration with health care professionals, and managing illness within the context of everyday life.

Two definitions specific to self-management of chronic kidney disease were found in the literature. Curtin and Mapes (2001) defined the self-management of chronic kidney disease as "the positive efforts of patients to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyle" (p. 386). The National Kidney Foundation (2013) clinical practice guidelines described self-management as a patient-centered "theory based approach" to disease prevention and management. These definitions are consistent with self-management and self-care further demonstrating that both concepts hold similar meanings.

Another usage for self-management and/or self-care of chronic kidney disease was found in the literature. The phrase self-care dialysis was common and described conducting either peritoneal dialysis or hemodialysis in the home without supervision from health care professionals (Lobbedez et al., 2012; Malmstrom et al., 2008; McLaughlin, Manns, Mortis, Hons & Taub, 2003; Moran, 2007; Pagels, Wang & Wengstrom, 2008; Parsons et al., 2006; Perras & Zappacosta, 1982; Piccoli et al., 2001; Piccoli et al., 2005; Polaschek, 2005). Home dialysis requires high levels of autonomy and the enactment of many characteristics associated with self-management. As such, the concept and therapy were united to form a 'catch phrase'. The health economic literature refers to this form of therapy as independent dialysis or home dialysis (Manns, Mendelssohn & Taub, 2007; Pipkin et al., 2010). Both phrases accurately describe this form of therapy and reduce the use of self-management in the literature.

To review, self-management and self-care are similar concepts. Though the literature review demonstrated disparity among definitions recurring attributes, antecedents and consequences were evident. The following sections will elaborate.

Attributes

The third step required the determination of attributes most frequently associated with self-management of chronic kidney disease. Tables developed during phase two of the data selection process revealed clusters of characteristics and repetition of findings. The data were extensively reviewed and revised to ascertain attributes that distinguished self-management from other concepts (Walker & Avant, 2011). The following five attributes were identified: i) collaborative partnerships, ii) self-advocacy, iii) self-monitoring, ii) illness-related activities, and v) normalcy. A detailed explanation of each is outlined below. Appendix A provides a diagrammatic representation of the concept.

Collaborative partnerships

Collaborative partnerships are a fundamental characteristic associated with the self-management of chronic kidney disease. Patients and health care professionals (registered nurses, physicians, pharmacists, dietitians) work toward mutually derived disease management strategies tailored to fit the specific needs of the individual (Curtin, Sitter, Schatell, & Chewning, 2004; Curtin, Mapes, Schatell, Burrows-Hudson, 2005; Curtin et al., 2008; Denyes, Orem & SozWiss, 2001; Lorig & Holman, 2003; Molzahn et al., 2008; Pagels et al., 2008). A team approach is critical for patients with chronic kidney disease as the treatment including dietary changes, fluid restrictions and medication requirements, significantly alters one’s lifestyle. These treatment demands become more stringent as the illness progresses (Curtin et al., 2005).

Collaborative partnerships are achieved by supporting well-informed patients to select from various treatment options (Curtin et al., 2005; Lorig & Holman, 2003). Once chosen patients and health care professionals identify problems, set goals and construct plans to resolve issues associated with the disease (Chan, Wong & Chow, 2010; Lorig & Holman, 2003; Molzahn et al., 2008; Orem, 1985; Orem, 1995, Orem & Vardiman, 1995; Tsay & Hung, 2004). Patients must become experts of their own illness and consult with care professionals to seek solutions for symptoms, side effects and technical concerns (Curtin et al., 2005; Curtin et al., 2008). Such relationships encourage patients to attain and maintain independence within the health care system (Orem, 1985).

Self-advocacy

Self-advocacy pushes the boundaries of collaborative partnerships and suggests that patients assert their own preferences regarding care (Curtin & Mapes, 2001; Curtin, Sitter et al., 2004; Curtin et al., 2008; Sakraida & Robinson, 2009). Research indicated that patients informed health care professionals when interventions could be performed better or were completed incorrectly. If deemed necessary, second opinions were sought or complaints taken to higher authorities (Curtin, Sitter et al., 2004; Curtin et al., 2008). Patients needed to seek out information (internet, television, 800 numbers) autonomously to support their assertions (Curtin, Sitter et al., 2004; Lorig & Holman, 2003). Further patients must have high levels of confidence to pursue such endeavors and broach discussions with care professionals (Sakraida & Robinson, 2009). Curtin and Mapes (2001) found that patients wanted to refrain from upsetting health care professionals and damaging the relationship when practicing self-advocacy.

Some patients described the “health care system as the most formidable challenge” (Curtin & Mapes, 2001, p. 390) when trying to effectively advocate for themselves. Patients must be strongly motivated to act on their own behalf to secure the care they deem important for themselves. When patient concerns were not addressed to their satisfaction other avenues were explored. These included non-adherence to the treatment regimes or consulting alternative therapy experts. It is likely that patients concealed these actions from health care professionals (Curtin & Mapes, 2001).

Self-monitoring

Self-monitoring has been described as the observation (Denyes et al., 2001) and appraisal of physiological signs (Orem & Vardiman, 1995) related to the illness and one’s general health state (Orem, 1985; Orem, 1995). This complex cognitive process involves acute awareness of bodily cues and making judgments (Denyes et al., 2001; Orem &

Vardiman, 1995) around how to manage symptoms (Curtin & Mapes, 2001; Curtin, Sitter et al., 2004; Thomas-Hawkins & Zazworsky, 2005). Patients are expected to vigilantly track physical symptoms such as shortness of breath, edema, gastrointestinal discomfort, pruritus and dizziness (Brunier, 1990; Curtin & Mapes, 2001; Pagels et al., 2008). As well, the emotional sequela of chronic disease entails monitoring one's affect for signs of anxiety or depression (Bordin, Casati, Sicolo, Zuccherato, & Eduati, 2007; Brunier, 1990; Thomas-Hawkins & Zazworsky, 2005). Patients must have the capacity to accurately recognize symptoms and make choices that promote positive clinical outcomes (Curtin & Mapes, 2001; Smith et al., 2010). Considerable disease related knowledge is essential to effectively execute self-monitoring (Bordin et al., 2007; Curtin & Mapes, 2001).

Illness-related activities

Illness-related activities involve the performance of deliberate actions aimed at regulating chronic kidney disease (Denyes et al., 2001). According to Orem & Vardiman (1995) validated activities proven to ameliorate the effects of the disease should be practiced. Lorig & Holman (2003) suggested establishing an action plan with patients that specifically itemizes which activities will be performed. The plan of action should include illness-related activities that are consistent with the abilities of the patient (Orem, 1985). This practical approach clearly delineates the boundaries of responsibility. An important step for patients with chronic kidney disease as the performance of numerous illness-related activities on a daily basis is required. Other comorbid conditions such as, heart disease and diabetes are often present (Cardiac Care Network of Ontario, 2012; CORR, 2011) necessitating the practice of additional tasks. Illness-related activities may include measuring blood glucose, blood pressure and body weight and executing diet and medication regimes (Curtin, Sitter et al., 2004; Curtin et al., 2008). Patients must be adept at using technology to participate, as the above activities require the operation of glucose monitors and blood pressure equipment (Smith et al., 2010). For patients who perform their own dialysis therapy at home, the number of illness-related activities and use of technology is far more extensive (Curtin, Johnson et al., 2004). These patients independently connect and disconnect themselves from the dialysis machine, adjust the prescription, care for the vascular access site, and maintain the equipment (Curtin, Johnson et al., 2004).

Normalcy

Normalcy denotes the incorporation of self-management “into the pattern of daily living” (Orem, 1980, p. 231). Patients need to reconcile the numerous constraints characterized by the self-management of kidney disease with occupational responsibilities, social roles, and other demands of everyday life (Curtin, Johnson et al., 2004; Orem, 1985; Orem, 1995; Polaschek, 2005). The literature suggested that patients find a ‘new normal’ by changing behaviors to fit with the limitations symptoms and treatment regimes imposed (Curtin, Mapes, Petillo & Oberley, 2002; Lorig & Holman, 2003). For example, patients may bring their own meals to family gatherings to avoid consuming foods not on their diet. Others contend that teaching patients to dialyze at home supports normalcy (Loos-Ayav et al., 2008; Polaschek, 2005). Home therapies give patients greater flexibility over the scheduling of dialysis treatments and other aspects of care (Curtin, Johnson et al., 2004; Loos-Ayav et al., 2008). Regardless of the dialysis therapy, patients with a positive attitude who view behavior adjustments as life extending are more likely to achieve normalcy (Curtin et al., 2002).

Model case

The next step in the concept analysis is to construct a model case that illustrates all the attributes of self-management. Walker & Avant (2011) suggest that the model case can be taken from clinical experiences, the literature (Pagels et al., 2008) or constructed by the writer. All these elements were combined and adapted to build a model case.

A 55 year old male (Mr. Smith) diagnosed with diabetes, hypertension and stage three chronic kidney disease is followed at a nurse-led, interprofessional renal clinic. The patient works in sales and travels extensively. The nurse has collaborated with the patient to identify problems and determine disease management goals that fit with Mr. Smith's lifestyle. The nurse explained the importance of blood glucose and blood pressure monitoring and following a diabetic, renal friendly diet. Mr. Smith expressed great concern regarding self-management and asserted that given his busy schedule regularly following the treatment regimes was difficult. Mr. Smith independently sought out methods to self-monitor and track symptoms. Mr. Smith proposed the use of an application on his phone to track blood glucose and blood pressure readings. With the support of the dietitian, Mr. Smith developed a library of information on his phone regarding recipes and menu options at restaurants that fit with the diet recommendations.

All attributes of self-management occur in the case. Collaborative partnerships were established between Mr. Smith, the nurse, and the dietitian to identify problems and devise goals that support positive clinical outcomes. The patient demonstrated self-advocacy expressing concerns over the feasibility of the treatment regime and independently found a solution through the use of an electronic application. This approach also helped Mr. Smith to self-monitor symptoms and track illness-related activities including measuring blood glucose and blood pressure. Normalcy was achieved by using technology to make food choices consistent with the treatment plan and his busy schedule.

Borderline and related cases

Borderline and related cases were constructed, as per the Walker and Avant framework (2011). A borderline case refers to those instances where two concepts contain all or most of the same attributes but differ significantly in some way. No borderline cases were found for the self-management of adults with chronic kidney disease. Though some may contend that self-management and self-care are borderline cases, this concept analysis purports that both concepts are similar and no substantial differences are evident.

Related cases represent examples that contain some but not all attributes (Walker & Avant, 2011). Empowerment is a related concept with attributes that include mutual participation, active listening and individualized knowledge acquisition (Ellis-Stoll & Popkess-Vawter, 1998). The concepts of empowerment and self-management are similar with regards to collaborative partnerships with health care professionals. The attribute individualized knowledge acquisition is similar to the self-advocacy of self-management as both describe actively seeking information that supports one’s health (Ellis-Stoll & Popkess-Vawter, 1998). The attributes distinct to self-management are the self-monitoring and illness-related activities where patients engage in the observation and performance of healthful actions. Some examples include exercise, diet, and blood pressure measurement.

Contrary, invented and illegitimate cases

An example of a contrary case is an unconscious patient admitted to the intensive care unit connected to mechanical ventilation. The patient is unable to move or speak and is entirely dependent on health care professionals to provide supports that sustain life. Clearly, this is not a case indicative of self-management (Walker & Avant, 2011).

Other cases including invented and illegitimate were not included in this concept analysis. Walker & Avant (2011) explicitly state that not all analyses benefit from the description of invented cases. The use of invented examples would not provide further clarification and were omitted.

Antecedents and Consequences

The next step is identification of the antecedents and consequences associated with the self-management of chronic kidney disease. The antecedents are physical competence, cognitive ability, education, and resources. Physical competence was seldom noted in the literature however, its importance should not be overlooked. The numerous tasks involved in the execution of illness-related activities means patients must have adequate vision and use of their hands to complete tasks independently. As well, patients need to travel to treatment centers and medical appointments and stand on weight scales (Denyes et al., 2001; Orem, 1985; Yodchai, Dunning, Hutchinson, Oumtanee & Savage, 2011). Physical capacity is used as a criterion to determine eligibility for home dialysis, as patients must be able to manipulate equipment needed to perform treatments (Loos-

Ayav et al., 2008). Often the presence of other comorbid conditions may cause further impairments to physicality. As illness severity increases patients may develop deficits necessitating assistance from health care professionals, family members or other services impacting ability to self-management (Curtin, Johnson et al., 2004).

The spectrum of cognitive abilities necessary to actively participate in self-management includes mental competence (Denyes et al., 1995; Orem, 1985), motivation (Bordin et al., 2007; Brunier, 1990; Smith et al., 2010; Tsay & Hung, 2004) and self-efficacy (Curtin, Sitter et al., 2004; Curtin et al., 2008; Lorig & Holman, 2003; Thomas-Hawkins & Zazworsky, 2005). Mental competence is fundamental for self-management. Patients must be able to make decisions and judgments regarding treatment options, monitoring symptoms and understanding what actions are needed to mitigate illness effects (Denyes et al., 1995; Orem, 1985). For patients dialyzing at home, equipment operation and safe manipulation of treatment regimes requires high cognitive functioning (Loos-Ayav et al., 2008). Further patients must exhibit motivation to participate in self-management and adhere to the many restrictions associated with the treatment regimes (Bordin et al., 2007; Brunier, 1990; Smith et al., 2010). In addition to motivation, self-efficacy supports patient self-management (Lorig & Holman, 2003). Self-efficacy means patients have confidence in their ability to participate in self-management and that those actions will improve outcomes (Curtin, Sitter et al., 2004; Curtin et al., 2008; Thomas-Hawkins & Zazworsky, 2005). Research indicated that patients with higher levels of self-efficacy are more likely to successfully engage in self-management (Curtin et al., 2008).

The complexity of the disease and activities related to its management requires disease specific knowledge (Blakeman, Protheroe, Chew Graham, Rogers & Kennedy, 2012; Denyes et al., 1995; Orem, 1985; Pagels et al., 2008). Education is particularly important as patients with chronic kidney disease do not feel overt symptoms, obscuring the need for treatment and behavior modification. The presence of other comorbidities compounds the information patients require (Molzahn et al., 2008; Thomas-Hawkins & Zazworsky, 2005). Certain treatment options such as home dialysis necessitates extensive training for six to eight weeks. Patients must successfully complete tests before permitted to transfer home (Bordin et al., 2007; Smith et al., 2010).

Several resources are required to facilitate self-management including family/friend support (Chan et al., 2010; Polaschek, 2005; Smith et al., 2010; Tsay & Hung, 2004), peer networks (Gillis et al., 1995; Hughes, Wood & Smith, 2009; Lorig & Holman, 2003; Smith et al., 2010; Thomas-Hawkins & Zazworsky 2005), housing and finances (Chan et al., 2010). Family members or friends may provide emotional support and assist with illness-related activities. For example, family may drive relatives to medical appointments, dialysis treatments, pick-up prescriptions and food shopping. Patients with physical or cognitive deficits may need extensive support from family. As well, patients wanting to dialyze at home must have someone present during all treatments (Chan et al., 2010; Polaschek, 2005; Smith et al., 2010; Tsay & Hung, 2004). Research indicated that peers helped patients adjust to the illness. Working with others that have learned to embrace life with kidney disease inspires patients to self-manage (Hughes et al., 2009; Lorig & Holman, 2003; Smith et al., 2010; Thomas-Hawkins &

Zazworsky, 2005). Adequate housing and financial stability are also essential for patients with chronic illness. Many treatments and services such as transportation, medication, and chiropody are out-of-pocket expenses for the patient. Hydro and electrical costs associated with home dialysis are not covered by medical insurance (Chan et al., 2010).

The consequences of self-management are slower disease progression (Sakraida & Robinson, 2009), improved clinical outcomes (Curtin, Sitter et al., 2004; Lorig & Holman, 2003) and higher quality of life (Chan et al., 2010; Loos-Ayav et al., 2008). For patients with mild to moderate chronic kidney disease the goal of self-management is to slow disease progression. Research indicated that those with diabetes and hypertension, treatment preserved kidney function delaying the need for dialysis (Sakraida & Robinson, 2009). Further self-management programs have demonstrated improved medication adherence, and other health variables (Curtin, Sitter et al., 2004; Lorig & Holman, 2003). Patients' self-reported quality of life is higher for those that practiced self-management (Chan et al., 2010; Loos-Ayav et al., 2008).

Empirical referents

The last step is determination of empirical referents. According to Walker and Avant (2011) the empirical referents are the measurement of the defining attributes and not the entire concept. This is an important distinction as the literature demonstrated that many researchers measured the antecedents and consequences of self-management. Some examples included scales to measure self-efficacy and quality of life (Bodenheimer et al., 2002; Griva et al., 2011; Lorig et al., 1999).

The means of measuring the attributes of self-management may include qualitative, quantitative and mixed methods. Semi-structured interviews or focus groups may be utilized to evaluate the effects of collaborative relationships with health care professionals and self-advocacy. The perception of these interactions may impact its measurement, thus the challenge for researchers is to devise robust designs that accurately captures the dynamic processes.

No instruments that measure self-management of chronic kidney disease were found. For other conditions including heart disease and diabetes, scales measuring self-management are available. Some examples included Self-Care of Heart Failure Index (Riegel et al., 2004) and Diabetes Self-Management Instrument (Lin, 2005). These tools may or may not be appropriate for use within the chronic kidney disease population. Further research is needed to develop standardized, valid measurements that capture all attributes of self-management (Kaptein et al., 2010).

Discussion

Strengths and Limitations of Concept Analysis

The conceptual analysis was a challenging endeavor made more complex by the abundance of literature that required organization and synthesis. As well, the inconsistencies amongst findings made comparative analysis difficult. For these reasons careful consideration of the strengths and limitations of this concept analysis was a worthwhile exercise (Fawcett, 1995; Fawcett, 2005; Walker & Avant, 2011).

Strengths of the concept analysis include parsimony (Fawcett, 2005). Walker and Avant (2011) stated that the concept must be differentiated from others using the fewest attributes possible. Though a specific number was not recommended, Walker and Avant (2011) reference two analyses that contain four to six attributes as ideal examples. This analysis demanded five attributes based on the literature review to distinguish it from other concepts. An appropriate number based on the Walker and Avant (2011) guidelines. The related case highlights the importance of the self-monitoring and self-care activities attributes. These characteristics are exclusive to the self-management of chronic kidney disease.

Despite the uniqueness and small number of attributes, the breadth of each characteristic is vast (Walker & Avant, 2011). This conceptual limitation is concerning as adults with chronic kidney disease must often attend to issues related to other vascular conditions (CORR, 2011; Heart and Stroke Foundation, 2010). Is it reasonable for patients to engage in all five attributes of self-management for kidney disease when diabetes and cardiovascular illness are also present? Such answers are difficult to discern particularly given the lack of comparative research findings. For patients and nurses forming collaborative partnerships may be advantageous when multiple comorbidities are present as it provides excellent opportunity to address issues holistically (Molzahn et al., 2008; Pagels et al., 2008). However, self-advocacy, self-monitoring, illness-related activities and normalcy would be challenging. For example, the illness-related activities associated with diabetes commonly include medications, diet restrictions and blood glucose monitoring. When the patient is also diagnosed with chronic kidney disease the number of medications required and complexity of the diet and activities increases significantly. Patients may find it more difficult to incorporate these numerous aspects into their lifestyle. Caution must be taken to avoid constructing concepts that are unattainable. Nurses, in collaboration with other health care professionals, need to determine how concepts can be integrated into practice, policy and research (Jessee et al., 2012; Molzahn et al., 2008; Morgan et al., 2009; Tshiananga et al., 2012; Watts et al., 2009).

Implications for Nursing Practice, Policy and Research

Nursing practice that includes motivational interviewing, disease specific education, and referral to community resources (peer networks) provides support for the antecedents of self-management. Other interventions such as collaboration, goal setting and feedback facilitate the attributes of self-management (Molzahn et al., 2008; Sol, van der Bijl, Banga & Visseren, 2005; Watts et al., 2009). This multiplicity is imperative given the complex and insidious nature of renal disease. Patients with mild to moderate chronic kidney disease believe that illness management is unnecessary due to the absence of symptoms. These patients require considerable education to understand the magnitude of the illness and encouragement to participate in treatments that slow disease progression (Byrne, Khunti, Stone, Farooqi, & Carr, 2011; Curtin et al., 2008). For those with advanced kidney disease, following the increasingly strict treatment regimes is difficult (Eldh, Ehnfors & Ekman, 2006). Eldh et al (2006) found that nonadherence was related to perceived lack of respect for the patient and life context. Therefore, nursing practice must balance the patients’ perspectives with the illness demands. In collaboration with other health care professionals nurses can integrate all medical recommendations with the patients’ preferred lifestyle to promote self-management (Sol et al., 2005).

Health care policies that facilitate interventions aimed at enhancing patient self-management are needed. For example, Molzahn et al (2008) reported that nurse-led clinics implementing practices consistent with the antecedents and attributes of self-management were effective. Other initiatives have failed to provide comprehensive access to therapies aimed at supporting self-management. The Ontario Renal Network set a strategic goal that 40% of all end stage renal patients would dialyze using a home-based therapy (Visaya, 2010). Research demonstrated that patients deemed competent to dialyze at home are young, well educated and have higher socioeconomic status, less severe kidney disease and fewer comorbidities. Though home based therapies improved patient outcomes, the selection bias highlights inequity within the health care system (Loos-Ayav et al., 2008; Woods et al., 1996). Nurses must advocate for policies that address the entire chronic kidney disease population from early stages to end stage failure.

The disconnect between nursing practice and health care policy may be related to the numerous inconsistencies within the self-management literature. This concept analysis revealed disagreement amongst researchers regarding what constitutes the antecedents and attributes of self-management (Curtin & Mapes, 2001; Lorig & Holman, 2003; Orem, 1985). Bodenheimer et al (2002) noted that strategies used to teach self-management were so diverse that determining effectiveness was not feasible. Further the utilization of related concepts such as empowerment to conduct research on self-management makes comparative analysis of nursing interventions difficult (Tsay & Hung, 2004). Clear delineation of terminology, antecedents and attributes is critical to ascertain which strategies are most advantageous for the self-management of chronic kidney disease. As well, researchers are unable to determine whether a single nursing intervention is effective or combinations of supports are needed to enhance patient self-management. Such findings are vital to establish consistent standards of nursing practice and supportive policies.

Consensus regarding the conceptualization of self-management would facilitate the development of measurement tools. Nurse researchers need validated instruments to measure interventions and clinical outcomes. Quantitative data of nursing practices is fundamental to influence health policies that support patient self-management.

Recommendations for Future Concept Development

This analysis prompts an interesting question – Is the conceptualization of self-management for adults with chronic kidney disease germane to all chronic illnesses? A brief review of concept models of self-management in chronic illness suggested that similarities are evident (Embrey, 2006; Hugh, 2010; Kawi, 2012). Embrey (2006), Hugh (2010), and Kawi (2012) indicated that collaborative partnership, monitoring, and illness-related activities are characteristics associated with chronic illness self-management. Rothenberger's (2011) concept model of self-management in prediabetes was examined as the illness is a common comorbidity of chronic kidney disease. Interestingly, this analysis and the Rothenberger (2011) findings demonstrated numerous congruencies. These included the attributes of collaboration with health care professionals, self-monitoring and normalcy. As well, the antecedents were knowledge and self-efficacy and consequence was slowing disease progression (Rothenberger, 2011). The literature suggests that a single conceptualization of self-management in chronic illness is plausible.

This analysis provides clarity on the conceptualization of self-management for adults with chronic kidney disease. The model clearly separates the antecedents, attributes and consequences of self-management. Examination of usage demonstrated that self-management and self-care are similar concepts. As such, one term should be utilized to reduce ambiguity and support consistency of nursing practice, policy and research. Future investigations are needed to determine which strategies, interventions and services would best promote self-management of chronic kidney disease with and without the presence of other comorbidities.

References

Blakeman, T., Protheroe, J., Chew Graham, C., Rogers, A., & Kennedy, A. (2012). Understanding the management of early-stage chronic kidney disease in primary care: A qualitative study. *British Journal of General Practice, 62*(597), e233-e242. doi: http://dx.doi.org/10.3399/bjgp12X636056

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of American Medical Association, 288*(19), 2169-2175.

Bordin, G., Casati, M., Sicolo, N., Zuccherato, N., & Eduati, V. (2007). Patient education in peritoneal dialysis: An observational study in Italy. *Journal of Renal Care,* 165-171.

Brunier, G. (1990). Appraising and monitoring a life on dialysis. *CANNT journal*, 15-17.

Byrne, J., Khunti, K., Stone, M., Farooqi, A., & Carr, S. (2011). Feasibility of a structured group education session to improve self-management of blood pressure in people with chronic kidney disease: An open randomised pilot trial. *BMJ Open, 1*(2), e000381. doi: http://dx.doi.org/10.1136/bmjopen-2011-000381

Canadian Organ Replacement Register (2011). *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2000-2009*. Retrieved from http://secure.cihi.ca/cihiweb/products/2011_CORR_Annual_Report_final_e.pdf.

Cardiac Care Network of Ontario (2012). *Shaping the future of vascular health: An integrated vascular health blueprint for Ontario*. Retrieved from http://www.opha.on.ca/Integrated% 20Vascular%20Health%20Blueprint%20for%20Ontario_August%202012.pdf.

Case Western Reserve University (2009). *Center for excellence for self-management advancement through research and translation*. Retrieved from http://fpb.case.edu/SMART Center/selfmgmt.shtm

Chan, M. F., Wong, F. K. Y., & Chow, S. K. Y. (2010). Investigating the health profile of patients with end-stage renal failure receiving peritoneal dialysis: A cluster analysis. *Journal of Clinical Nursing, 19*(5-6), 649-657. doi: http://dx.doi.org/10.1111/j.1365-2702.2009.03103.x

Curtin, R. B., Johnson, K., & Schatell, D. (2004). The peritoneal dialysis experience: Insights from long-term patients. *Nephrology Nursing Journal, 31*(6), 615-625.

Curtin, R. B. & Mapes, D. (2001). Health care management strategies of long-term dialysis survivors. *Nephrology Nursing Journal, 28*(4), 385-394.

Curtin, R. B., Mapes, D., Petillo, M., & Oberley, E. (2002). Long-term dialysis survivors: A transformational experience. *Qualitative Health Research, 12*(5), 609-624.

Curtin, R. B., Mapes, D., Schatell, D., & Burrows-Hudson, S. (2005). Self-management in patients with end stage renal disease: Exploring domains and dimensions. *Nephrology Nursing Journal, 32*(4), 389-395.

Curtin, R. B., Sitter, D. C. B., Schatell, D., & Chewning, B. A. (2004). Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Nephrology Nursing Journal, 31*(4), 378-396.

Curtin, R. B., Walters, B. A. J., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-efficacy and self-management behaviours in patients with chronic kidney disease. *Advances in Chronic Kidney Disease, 15*(2), 191-205.

Denyes, M. J., Orem, D. E., & SozWiss, G. B. (2001). Self-care: A foundational science. *Nursing Science Quarterly, 14*(1), 48-54.

Eldh, A. C., Ehnfors, M., & Ekman, I. (2006). The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing, 5*, 45-53. doi:10.1016/j.ejcnurse.2005.06.002.

Ellis-Stoll, C. C. & Popkess-Vawter, S. (1998). A concept analysis on the process of empowerment. *Advances in Nursing Science, 21*(2), 62-68.

Embrey, N. (2006). A concept analysis of self-management in long-term conditions. *British Journal of Neuroscience Nursing, 2*(10), 507-513.

Fawcett, J. (1995). *Analysis and evaluation of conceptual models of nursing*. (3rd Ed.) Philadelphia, PA: F. A. Davis Company.

Fawcett, J. (2005). Criteria for evaluation of theory. *Nursing Science Quarterly, 18*(2), 131-135.

Gillis, B. P., Caggiula, A. W., Chiavacci, A. T., Coyne, T., Doroshenko, L., Milas, N. C., . . . Scherch, L. K. (1995). Nutrition intervention program of the modification of diet in renal disease study: A self-management approach. *Journal of the American Dietetic Association, 95*(11), 1288-1294. doi: http://dx.doi.org/10.1016/S0002-8223%2895%2900338-X

Greenfield, E. & Pace, J. C. (1985). Orem's self-care theory of nursing: Practical application to the end stage renal disease (ESRD) patient. *Journal of Nephrology Nursing*, 187-193.

Griva, K., Mooppil, N., Seet, P., Krishnan, D. S., James, H., & Newman, S. P. (2011). The NKF-NUS hemodialysis trial protocol – a randomized controlled trial to determine the effectiveness of a self management intervention for hemodialysis patients. *BCM Nephrology, 12*(4). doi:10.1186/1471-2369-12-4.

Gruman, J. & Von Korff, M. (1996). *Indexed bibliography on self-management for people with chronic disease*. Washington DC: Center for Advancement in Health.

Heart and Stroke Foundation (2010). *A perfect storm of heart disease looming on the horizon: 2010 Heart and Stroke Foundation annual report on Canadians' health.* Retrieved from http://www.heartandstroke.com/atf/cf/%7B99452D8B-E7F1-4BD6-A57D-B136CE6C95BF%7D/Jan23_EN_ReportCard.pdf.

Hugh, L. (2010). *Chronic disease self-management: An evolutionary concept analysis*. Retrieved from http://dspace.library.uvic.ca:8080/bitstream/handle/1828/4057/Hughes_ Lori_MN_2010.pdf?sequence=1.

Hughes, J., Wood, E., & Smith, G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations, 12*, 396-406. doi: 10.1111/j.1369-7625.2009.00568.x

Jessee, B., Thomas, & Rutledge, C. M. (2012). Effectiveness of nurse practitioner coordinated team group visits for type 2 diabetes in medically underserved

Appalachia. *Journal of the American Academy of Nurse Practitioners, 24*(12), 735-743. doi: 10.1111/j.1745-7599.2012.00764.x

Kaptein, A. A., van Dijik, S., Broadbent, E., Falzon, L., Thong, M., & Dekker, F. W. (2010). Behavioural research in patients with end-stage renal disease: A review and research agenda. Patient Education and Counseling, 81, 23-29. doi: 10.1016/j.pec.2009.10.031.

Kawi, J. (2012). Self-management support in chronic illness care: A concept analysis. *Research and Theory for Nursing Practice: An International Journal, 26*(2), 108-125.

Kidney Foundation of Canada (2013). Facing the facts: Includes highlights from the Canadian Organ Replacement Register, 2013. Retrieved from http://www.kidney.ca/document.doc?id= 4083

Krespi, R., Bone, M., Ahmad, R., Worthington, B., & Salmon, P. (2004). Haemodialysis patients' beliefs about renal failure and its treatment. *Patient Education and Couseling, 53*, 189-196.

Lavis, J. N., & Boyko, J. A. (2009). *Evidence brief: Strengthening chronic disease management in Ontario*. Hamilton, Ontario: McMaster Health Forum.

Lin, C. C. (2005). *Development and testing of the diabetes self-management instrument*. Unpublished doctoral dissertation, The University of Michigan.

Lobbedez, T., Verger, C., Ryckelynck, J., Fabre, E., & Evans, D. (2012). Is assisted peritoneal dialysis associated with technique survival when competing events are considered? Clinical Journal of the American Society of Nephrology, 7, 612-618. doi: 10.2215/CJN.10161011

Loos-Ayav, C., Frimat, L., Kessler, M., Chanliau, J., Durand, P., & Briancon, S. (2008). Changes in health-related quality of life in patients of self-care vs. in-center dialysis during the first year. *Quality of Life Research, 17*(1), 1-9. doi: http://dx.doi.org/10.1007/s11136-007-9286-1

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definitions, outcomes, and mechanisms. *Annals in Behavioral Medicine, 26*(1), 1-7.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P., Gonzalez, V. M., Laurent, D. D., & Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care, 37*(1), 5-14.

Mahnensmith, R. L., Zorzanello, M., Hsu, Y., & Williams, M. E. (2010). A quality improvement model for optimizing care of the diabetic end-stage renal disease patient. *Seminars in Dialysis, 23*(2), 206-213. doi: 10.1111/j.1525-139X.2010.00717.x.

Malmstrom, R. K., Roine, R. P., Heikkila, A., Rasanen, P., Sintonen, H., Muroma-Karttunen, R., & Honkanen, E. (2008). Cost analysis and health-related quality of life of home and self-care satellite haemodialysis. *Nephrology Dialysis Transplantation, 23*(6), 1990-1996. doi: http://dx.doi.org/10.1093/ndt/gfm910

Manns, B. J., Mendelssohn, D. C., & Taub, K. J. (2007). The economics of end-stage renal disease care in Canada: Incentives and impact on delivery of care.

International Journal of Health Care Finance Economics, 7, 149-169.

McLaughlin, K., Manns, B., Mortis, G., Hons, R., & Taub, K. (2003). Why patients with ESRD do not select self-care dialysis as a treatment option. *American Journal of Kidney Diseases, 41*(2), 380- 385.

Molzahn, A. E., Hibbert, M. P., Gaudet, D., Starzomski, R., Barrett, B., & Morgan, J. (2008). Managing chronic kidney disease in a nurse-run, physician-monitored clinic: The CanPREVENT experience. *Canadian Journal of Nursing Research, 40*(3), 96-112.

Moran, J. (2007). The resurgence of home dialysis therapies. *Advances in Chronic Kidney Disease, 14*(3), 284-289.

Morgan, M., Dunbar, J., Reddy, P., Coates, M., & Leahy, R. (2009). The true blue study: Is practice nurse-led collaborative care effective in the management of depression for patients with heart disease or diabetes? *BMC Family Practice, 10*, 46. doi: http://dx.doi.org/10.1186/1471-2296-10-46

National Kidney Foundation (2013). K/DOQI clinical practice guidelines on hypertension and antihypertensive agents in chronic kidney disease: Guideline 5 education on self-management behavior. Retrieved from http://www.kidney.org/professionals/kdoqi/ guidelines _bp/guide_5.htm

Orem, D. E. (1985). A concept of self-care for the rehabilitation client. *Rehabilitation Nursing Journal, 10*(3), 33-36.

Orem, D. E. (1995). *Nursing: Concepts of practice*. (5th Ed.) St. Louis: Mosby-Year Book.

Orem, D. E. (1980, unpublished papers). Self-care and health promotion: Understanding self-care. In K. M. Renpenning & S. G. Taylor (Eds.), *Self-care theory in nursing: Selected papers of Dorothea Orem* (pp. 212-222). Springer Publishing Company: New York.

Orem, D. E. & Vardiman, E. M. (1995). Orem's nursing theory and positive mental health: Practical considerations. *Nursing Science Quarterly, 8*(4), 165-173.

Oxford Online Dictionary (2013a). *Self-management*. Retrieved from http://oxforddictionaries. com/definition/english/self--management.

Oxford Online Dictionary (2013b). *Self-care*. Retrieved from http://oxforddictionaries. com/definition/english/self--care.

Pagels, A. A., Wang, M., & Wengstrom, Y. (2008). The impact of a nurse-led clinic on self-care ability, disease-specific knowledge, and home dialysis modality. *Nephrology Nursing Journal, 35*(3), 242-248.

Parsons, T. L., Toffelmire, E. B., King-VanVlack, C. E. (2006). Exercise training during hemodialysis improves dialysis efficacy and physical performance. *Archives of Physical Medicine Rehabilitation, 87*, 680-687.

Perras, S. T., Zappacosta, A. R. (1982). The application of Orem's theory of promoting self-care in a peritoneal dialysis facility. *AANNT journal*, 37-39, 55.

Piccoli, G. B., Calderini, M., Bechis, F., Iadarola, A. M., Iacuzzo, C., Mezza, E., … Segoloni, G. P. (2001). Modelling the "ideal" self care – limited care dialysis center. *Journal of Nephrology, 14*, 162-168.

Piccoli, G. B., Mezza, E., Burdese, M., Consiglio, V., Vaggione, S., Mastella, C., … Piccoli, G. (2005). Dialysis choice in the context of an early referral policy: There is room for self care. *Journal of Nephrology, 18*(3), 267-275.

Pipkin, M., Eggers, P. W., Larive, B., Rocco, M. V., Stokes, J. B., Suri, R. S., & Lockridge, R. S. (2010). Recruitment and training for home hemodialysis: Experience and lessons from the nocturnal dialysis trial. *Clinical Journal of the American Society of Nephrology, 5,* 1614-1620. doi: 10.2215/CJN.02440310.

Polaschek, N. (2005). Haemodialysing at home: The client experience of self-treatment. *EDTNA/ERCA Journal*, 27-30.

Registered Nurses Association of Ontario (2010). *Best practice guideline - Strategies to support self-management in chronic conditions: Collaboration with clients*. Retrieved from http://rnao.ca/sites/rnao-ca/files/Strategies_to_Support_Self-Management_in_ Chronic_Conditions_-_Collaboration_with_Clients.pdf.

Riegel, B., Carlson, B., Moser, D. K., Sebern, M., Hicks, F. D., & Roland, V. (2004). Psychometric testing of the Self-Care of Heart Failure Index. *Journal of Cardiac Failure, (10)*4, 350-360.

Rothenberger, C. D. (2011). Chronic illness self-management in prediabetes: A concept analysis. *Journal of Nursing and Healthcare of Chronic Illness: An International Journal, 3*, 77-86. doi:10.1111/j.1752-9824.2011.01092.x

Sakraida, T. J., & Robinson, M. V. (2009). Health literacy self-management by patients with type 2 diabetes and stage 3 chronic kidney disease. *Western Journal of Nursing Research, 31*(5), 627-647. doi: 10.1177/0193945909334096

Smith, K., Coston, M., Glock, K., Elasy, T. A., Wallston, K. A., Ikizler, T. A., & Cavanaugh, K. L. (2010). Patient perspectives on fluid management in chronic hemodialysis. *Journal of Renal Nutrition, 20*(5), 334-341.

Sol, B. G. M., van der Bijl, J. J., Banga, J., & Visseren, F. L. J. (2005). Vascular risk management through nurse-led self-management programs. *Journal of Vascular Nursing*, *XXIII*(1), 20-24. doi: 10.1016/j.jvn.2004.12.003

Su, C., Lu, X., Chen, W., & Wang, T. (2009). Promoting self-management improves the health status of patients having peritoneal dialysis. *Journal of Advanced Nursing, 65*(7), 1381-1389. doi: http://dx.doi.org/10.1111/j.1365-2648.2009.04993.x

Tawney, K. W., Tawney, P. J. W., & Kovach, J. (2003). Disablement and rehabilitation in end-stage renal disease. *Seminars in Dialysis*, *16*(6), 447-452.

Thomas-Hawkins, C. & Zazworsky, D. (2005). Self-management of chronic kidney disease: Patients shoulder the responsibility for day-to-day management of chronic illness. How can nurses support their autonomy? *American Journal of Nursing, 105*(10), 40-48.

Tsay, S. L. & Hung, L. (2004). Empowerment of patients with end-stage renal disease – a randomized controlled trial. *International Journal of Nursing Studies, 41*, 59-65.

Tshiananga, J. K., Kocher, S., Weber, C., Erny-Albrecht, K., Berndt, K., & Neeser, K. (2012). The effect of nurse-led diabetes self-management education on glycosylated hemoglobin and cardiovascular risk factors: A meta-analysis. *Diabetes Educator, 38*(1), 108-123.

Visaya, M. A. (2010). Hemodialysis patients' perceptions of home hemodialysis and self-care. *CANNT Journal*, *20*(2), 23-28.

Walker, L. O. & Avant, K. C. (2011). *Strategies for Theory Construction in Nursing*. Upper Saddle River, NJ: Prentice Hall.

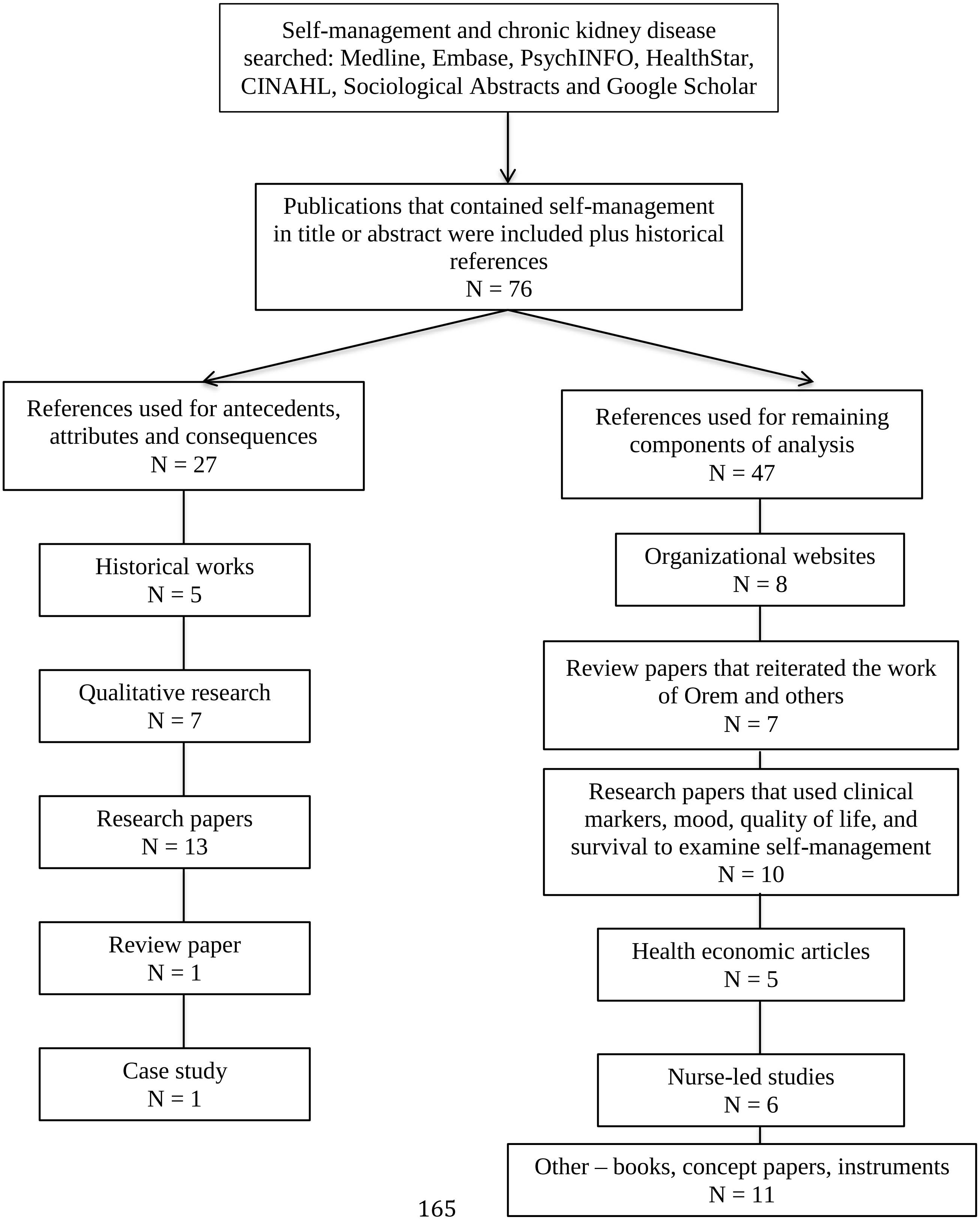
Watts, S. A., Gee, J., O'Day, M. E., Schaub, K., Lawrence, R., Aron, D., & Kirsh, S. (2009). Nurse practitioner-led multidisciplinary teams to improve chronic illness care: The unique strengths of nurse practitioners applied to shared medical appointments/group visits. *Journal of the American Academy of Nurse Practitioners, 21*(3), 167-172.

Woods, J. D., Port, F. K., Stannard, D., Blagg, C. R., & Held, P. J. (1996). Comparison of mortality with home hemodialysis and center hemodialysis: A national study. *Kidney International*, *49*(5), 1464-1470.

World Health Organization (1983). *Health education in self-care: Possibilities and limitations*. Retrieved from http://apps.who.int/iris/bitstream/10665/70092/1/HED_84.1.pdf.

Yodchai, K., Dunning, T., Hutchinson, A.M., Oumtanee, A., & Savage, S. (2011). How do Thai patients with end stage renal disease adapt to being dependent on haemodialysis? A pilot study. *Journal of Renal Care, 37*(4), 216-223.

Table 1: Summary of Data Selection



Appendix A – Concept of self-management in chronic kidney disease: Antecedents, Attributes and Consequences

Antecedents

- Physical Competence
- Cognitive Ability
  - Motivation
  - Self-efficacy
- Education
- Resources
  - Family/friend support
  - Peer networks
  - Housing
  - Financing

Attributes

- Collaborative partnerships
- Self-advocacy
- Self-monitoring
- Illness-related activities
- Normalcy

Consequences

- Disease progression
- Clinical outcomes
- Quality of life

Appendix C: Content validity study package (Phase One)

McMaster University

St. Joseph's Healthcare
Hamilton

The Self-Management of Vascular Disease Amongst Adults Undergoing Dialysis: Development and Psychometric Evaluation

Principal Investigators:
Lucia Costantini, RN, CNeph(C), PhD candidate
McMaster University

PhD committee:
Dr. Gina Browne, RN, PhD, Hon LLD, FCAHS (chair person)
Professor, Nursing; Clinical Epidemiology & Biostatistics, Founder and Director, Health & Social Service Utilization Research Unit, McMaster University
Dr. Maureen Markle-Reid, RN, PhD
Associate Professor, School of Nursing, Acting Assistant Dean of Research, McMaster University
Dr. Lehana Thabane, PhD
Professor/Associate Chair, Department of Clinical Epidemiology & Biostatistics, Director, Biostatistics Unit, Centre for Evaluation Medicine, McMaster University
Dr. Stephen Birch, PhD
Professor, Department of Clinical Epidemiology & Biostatistics, McMaster University

Local Investigator:
Dr. Chris Rabbat, MD
Nephrologist, Medical Director, Kidney and Urinary Program, St. Joseph's Healthcare Hamilton

McMaster University

Hamilton Integrated Research Ethics Board
JUN 17 2014

St. Joseph's Healthcare Hamilton

Letter of Information for a Research Study

Title: "The Self-Management of Vascular Disease Amongst Adults Undergoing Dialysis: Development and Psychometric Evaluation "

Dear Nephrology Expert,

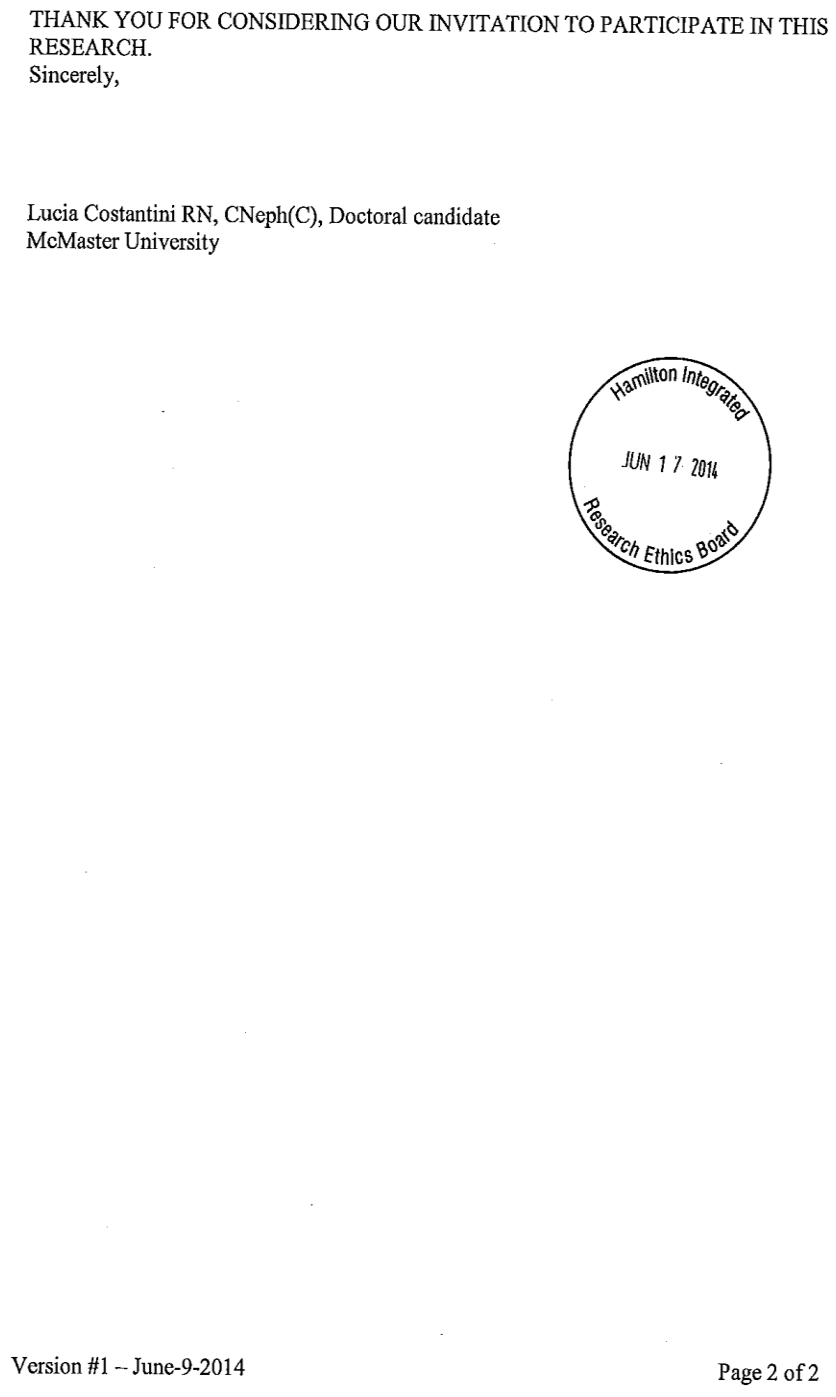
We are looking for nephrology experts to participate in the evaluation of the Vascular Disease Self-Management Instrument (V-SMI) for the purposes of testing the content validity of the tool. This study is being conducted by Lucia Costantini (doctoral candidate) and Drs. Gina Browne, Maureen Markle-Reid, Stephen Birch and Lehana Thabane from McMaster University.

This self-report instrument is designed to quantitatively measure the self-management undertaken by adults with vascular disease requiring dialysis. The tool would support the evaluation of interventions aimed at improving self-management. This research is part of PhD studies and comprises a component of the dissertation.

Your participation in the evaluation of the V-SMI is entirely voluntary and you may choose not to fill out the evaluation tool. If you choose to participate you will be asked to rate the items in the questionnaire as to their validity. We anticipate that this will take approximately one hour of your time. Completion of the evaluation package and return via self-addressed stamped envelope implies consent to participant in this study. Non-participation will in no way affect your future relationships and/or interactions with any person or institution involved in this study. You are assured complete anonymity; please do not include any identifying information within the package. Names will not be on study packages and there is no way to link your responses to you therefore, withdrawal is not possible once your evaluation has been received. Responses will be stored in a locked file for ten years and then destroyed (shredded). Only the research team will have access to your responses and only grouped responses will be used and reported at professional nursing conferences and in professional nursing journals.

The investigators do not know of any harm that may arise from participating in this study. Your participation in this study will help investigators to better assess the content validity of the tool. If you experience discomfort with any question please feel free to refuse to respond to any item in the package.

If you would like to participate, please fill out the enclosed V-SMI evaluation package and once completed mail back to us in the self-addressed stamped envelope. Should you require more information or have any questions, please contact Lucia Costantini at costal4@mcmaster.ca



THANK YOU FOR CONSIDERING OUR INVITATION TO PARTICIPATE IN THIS RESEARCH.

Sincerely,

Lucia Costantini RN, CNeph(C), Doctoral candidate
McMaster University

Hamilton Integrated
JUN 17 2014
Research Ethics Board

Version #1 – June-9-2014

Page 2 of 2

A reliable and valid instrument that measures the self-management of adults on dialysis with coexisting vascular conditions is essential. The *Vascular Disease Self-Management Instrument (V-SMI)* is a self-report tool that would facilitate the evaluation of health services and programs designed to support self-management. Self-management has been defined as "the positive efforts of patients to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyle" (Curtin & Mapes, 2001, p. 386). This definition highlights the components of self-management relevant to those with vascular conditions undergoing dialysis therapy. Other aspects of self-management such as, self-efficacy and psychological adaptation were not included in the V-SMI, as tools that measure these areas already exist.

Below, you will find a list of self-management subscales and definitions that guided the construction of this tool. As a content expert in the field, we ask you to perform the following three tasks:

1) **Link each item to its respective domain. The five domains are represented by (A), (B), (C), (D) and (E).**
2) **Assess the relevancy of each item to the domain and the domain's definition using a 4-point rating scale: (1) not relevant, (2) somewhat relevant, (3) quite relevant, and (4) very relevant.**
3) **Provide an overall judgment if you believe the items in the new tool adequately represent the content of the domain of self-management for**

adults with vascular disease requiring dialysis (a half page is provided for your comments).

THANK YOU VERY MUCH FOR YOUR TIME AND EXPERTISE!

The five subscales are defined as follows:

(A) Collaborative Partnerships – A reciprocal relationship amongst patients and health care providers (physicians, registered nurses, pharmacists, dietitians) aimed at the mutual determination of plans of care that fit with the specific needs of the individual. This includes discussing disease information, treatment plans, prognosis, test results and illness management strategies.

(B) Self-advocacy – The patients' vigilance over their illness and treatment. Here patients independently seek information on the disease and/or various treatment options, ask for support from family/friends and assert their own preference regarding treatment recommendations.

(C) Self-monitoring – The patients' observation of bodily cues and appraisal of physiological signs related to the illness and/or treatment. This cognitive process precedes taking action and may include tracking physical (shortness of breath, weight gain) and emotional (anxiety, depression) symptoms.

(D) Illness-related activities – The performance of specific actions intended to ameliorate symptoms, complete prescribed treatment recommendations, and maintain health. Patients' may engage in activities such as, measuring their blood pressure, preparing meals or taking medications.

(E) Normalizing – The capacity to adjust one's preferred lifestyle around the illness and treatment. Here the patient may alter their medication regime or dialysis treatments to fit with their work schedule or family roles (child care, socializing, etc.).

ITEMS

1) I can figure out which symptoms tell me the most about my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

2) I use alternative therapies (naturopathic doctor, acupuncture, etc.) to manage my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

3) I keep a record of how much fluid I gain between dialysis treatments.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

4) I adjust my eating to fit with other activities (e.g. going to a party, restaurant).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

5) I can figure out ways to manage my fatigue.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

6) I pay attention to how much weight I gain between dialysis treatments.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

7) I participate in making decisions about my treatment plan.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

8) When necessary, I figure out other ways to get the care I need.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

9) I follow a routine that fits with my preferred lifestyle (e.g. eating, sleeping, work).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

10) I try to be positive about my life in spite of my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

11) I talk to my health care provider about goals I would like to accomplish to improve my
health.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

12) I do things to take care of my dialysis access site.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

13) When I experience emotional symptoms (e.g. nervousness, sadness), I do things to help me feel able to manage.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

14) I find ways to protect my dialysis access site.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

15) I ask my health care providers (doctors, nurses, dieticians, pharmacist) for information about my treatment.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

16) I am comfortable talking to my health care providers about my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

17) I pay attention to how my dialysis treatment makes me feel (e.g. cramping, low blood pressure, nausea, vomiting).

<u>Subscale</u> (Circle the subscale that **most** applies)

A	B	C	D	E

<u>Relevancy</u>

Not relevant	Somewhat relevant	Quite relevant	Very relevant

18) I figure out ways to fit my dialysis therapy into my everyday life.

<u>Subscale</u> (Circle the subscale that **most** applies)

A	B	C	D	E

<u>Relevancy</u>

Not relevant	Somewhat relevant	Quite relevant	Very relevant

19) I am comfortable talking to my health care provider about ways to change my care (diet, medications, body weight) to better fit with my every day life.

<u>Subscale</u> (Circle the subscale that **most** applies)

A	B	C	D	E

<u>Relevancy</u>

Not relevant	Somewhat relevant	Quite relevant	Very relevant

20) I ask for a copy of my blood laboratory results.

<u>Subscale</u> (Circle the subscale that **most** applies)

A	B	C	D	E

<u>Relevancy</u>

Not relevant	Somewhat relevant	Quite relevant	Very relevant

21) I take my medications as it has been prescribed for me.

<u>Subscale</u> (Circle the subscale that **most** applies)

A	B	C	D	E

<u>Relevancy</u>

Not relevant	Somewhat relevant	Quite relevant	Very relevant

22) When I experience body symptoms (e.g. tiredness, thirst), I do things to help me feel better (stay calm, try to relax, take medication for pain).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

23) I talk to my health care provider to figure out ways to manage my symptoms (e.g. shortness of breath, fatigue, depression).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

24) I seek out written information about my illness and treatment.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

25) I pay attention to how I am feeling emotionally (e.g. tired, frustrated, angry, depressed).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

26) I adjust other responsibilities (e.g. work, household chores) in my life to fit with my dialysis treatment schedule.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

27) I ask my health care provider for help when I feel my illness is too hard to manage.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

28) I pay attention to events in my every day life that may cause my illness to get worse.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

29) I keep a record of my blood pressure readings.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

30) I pay attention to the foods I choose to eat.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

31) I pay attention to body signs and symptoms (e.g. difficulty breathing, changes in body weight, blood sugar level).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

32) I pay attention to body signs and symptoms (e.g. difficulty breathing, changes in body weight, blood sugar level).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

33) I change how much fluids I drink to fit with my everyday life.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

34) I try to find ways that make my life as normal as possible.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

35) I am comfortable asking others (family, friends, coworkers) for help with managing my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

36) I talk to other patients on dialysis for information about the illness and treatment.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

37) I talk to my health care providers to figure out ways to change my treatment plan when necessary.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

38) I can recognize when I need help from health care providers.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

39) I look for information on the Internet about my illness and treatment.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

40) I can usually figure out the reasons for changes of my symptoms (e.g. breathing, body weight, blood pressure).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

41) I ask for help from health care providers when I need it.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

42) I am comfortable talking to my health care providers about my test results (e.g. blood work, angiogram, x-rays).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

43) I alter my medication schedule to fit with other areas of life (e.g. socializing, work).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

44) I am comfortable talking to my health care providers about my treatment plan.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

45) I think of my medical appointments (e.g. going to dialysis, medical appointments) as a chance to socialize with other people.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

46) I think of my dialysis treatments as a way to stay healthy.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

47) I am comfortable telling my health care provider which treatment recommendations work best for me (e.g. how much fluid removal you can tolerate).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

48) I look for alternative therapy experts (naturopathic doctor, acupuncture, etc.) to help me manage my illness.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

49) I eat meals according to the recommended diet plan.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

50) I drink fluids as suggested by my health care providers.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

51) I participate in my dialysis treatments (e.g. weigh myself, take my temperature, connect myself to the machine).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

52) I pay attention to my blood laboratory results (potassium, phosphorous).

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

53) I figure out ways to make sure that my dialysis access site is protected.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

54) I pay attention to my medications and how they make me feel.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

55) I find ways to protect my dialysis access site.

Subscale (Circle the subscale that **most** applies)

A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

56) I ask my health care providers (doctors, nurses, dieticians, pharmacist) for information about my illness.

Subscale (Circle the subscale that **most** applies)

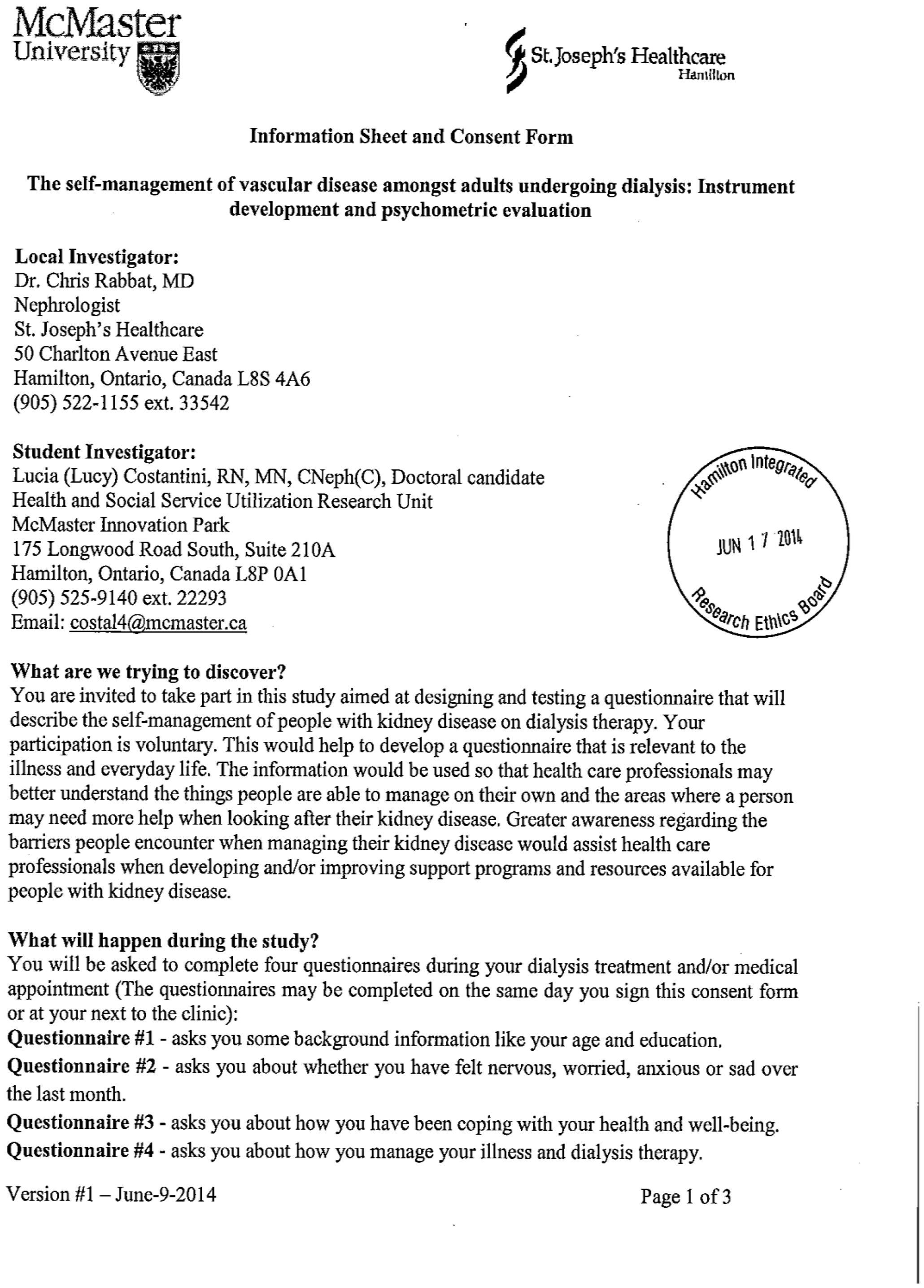
A	B	C	D	E

Relevancy

Not relevant	Somewhat relevant	Quite relevant	Very relevant

Provide an overall judgment and suggestions in order to make the items in the V-SMI adequately represent the content of self-management for adults with a vascular condition on dialysis. If you have suggestions regarding rephrasing the wording of items or adding items that you think are relevant please include them in the space provided below.

Appendix D: Information Sheet and Consent Form (Phase Two)



McMaster University

St. Joseph's Healthcare Hamilton

Information Sheet and Consent Form

The self-management of vascular disease amongst adults undergoing dialysis: Instrument development and psychometric evaluation

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Hamilton Integrated Research Ethics Board
JUN 17 2014

What are we trying to discover?
You are invited to take part in this study aimed at designing and testing a questionnaire that will describe the self-management of people with kidney disease on dialysis therapy. Your participation is voluntary. This would help to develop a questionnaire that is relevant to the illness and everyday life. The information would be used so that health care professionals may better understand the things people are able to manage on their own and the areas where a person may need more help when looking after their kidney disease. Greater awareness regarding the barriers people encounter when managing their kidney disease would assist health care professionals when developing and/or improving support programs and resources available for people with kidney disease.

What will happen during the study?
You will be asked to complete four questionnaires during your dialysis treatment and/or medical appointment (The questionnaires may be completed on the same day you sign this consent form or at your next to the clinic):

Questionnaire #1 - asks you some background information like your age and education.

Questionnaire #2 - asks you about whether you have felt nervous, worried, anxious or sad over the last month.

Questionnaire #3 - asks you about how you have been coping with your health and well-being.

Questionnaire #4 - asks you about how you manage your illness and dialysis therapy.

Completing all four questionnaires will take approximately 45 minutes to 1 hour. You may take as much time as you need and the questionnaires can be completed while you are receiving your dialysis therapy. After completing the questionnaires, I (or another member of the research team) will ask for your permission to return during your next dialysis session. If you say yes, I will ask you to complete **Questionnaire #4 only** during your next dialysis session. If no, the study has ended and we thank you for your participation.

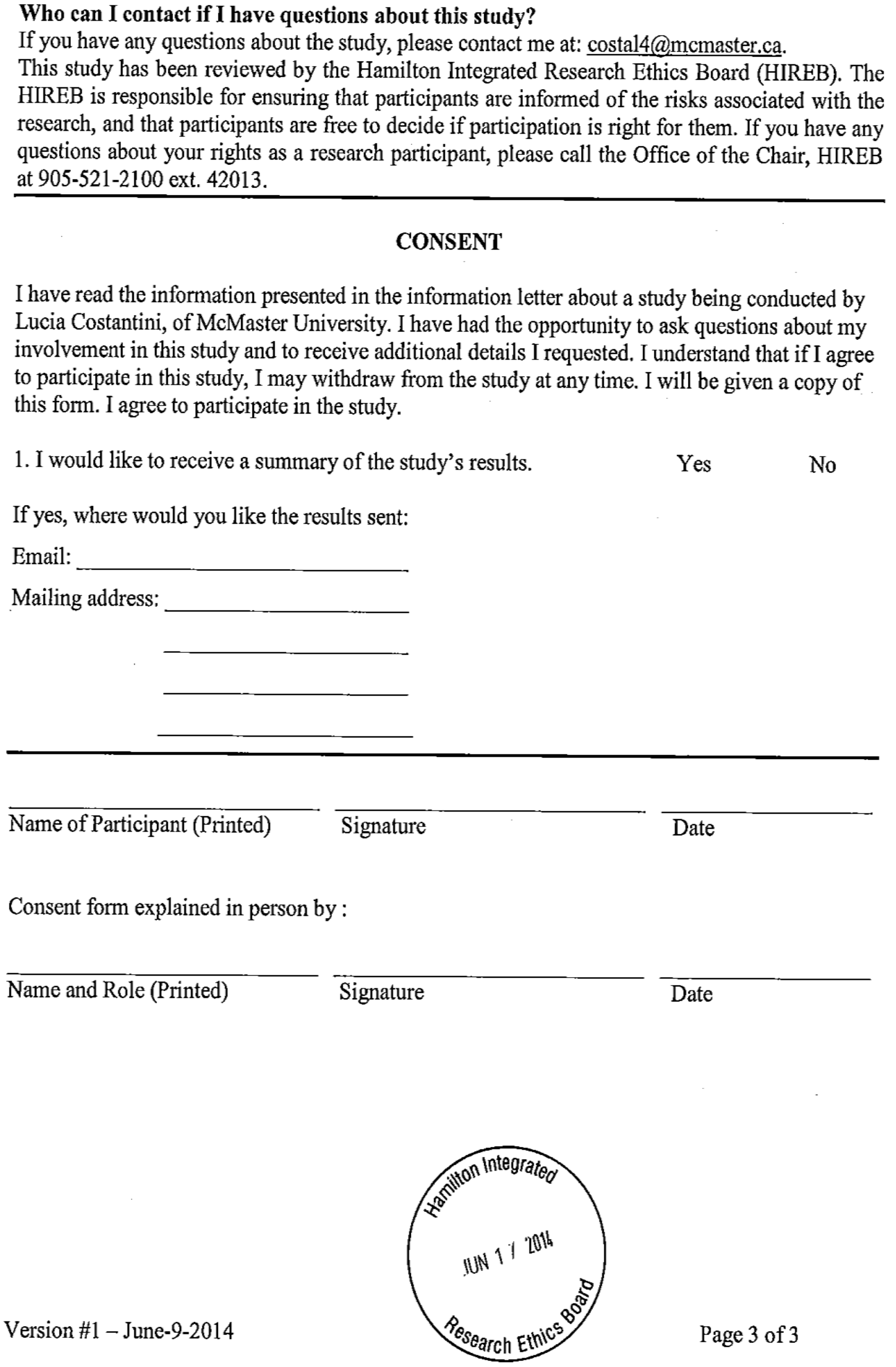
Are there any risks to doing the study?
The risks involved in participating in this study are minimal. You do not need to answer questions on the questionnaires that you do not want to answer or that make you feel uncomfortable. You may choose to withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study?
The research will not benefit you directly. We hope to learn more about the self-management of adults undergoing dialysis therapy. The results of the study would be used to develop a questionnaire that gathers information about things people do to self-manage when using dialysis services. In the future, information obtained from the self-management questionnaire could help to develop programs and services that support people on dialysis to manage their health and well-being.

Confidentiality
You are participating in this study confidentially. I will not disclose to any one that you are participating in the study. Since you will be in the clinic other people (nurses, doctors, etc.) may see you completing the questionnaires. However, this is a teaching and research hospital and participating in research is common. No names will be used on the study forms (questionnaires). Research forms (questionnaires) will be coded with numbers to ensure confidentiality. I will be the only one to see the names and coded numbers to protect your identity. Your responses to the questions will be entered into the computer for statistical analysis using the coded numbers. Once your responses have been entered into the computer your information will be anonymous and you cannot withdraw from the study as I will not be able to identify you. Consent forms and questionnaires will be kept in a locked cabinet that can only be accessed by myself or a member of the research team.

What if I change my mind about being in the study?
Your participation in completing this study is entirely voluntary. It is your choice to be part of the study or you may decide not to participate. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or partway through the study. If you decide to withdraw, there will be no consequence to you. Should you withdraw from the study, the information collected prior to your withdrawal will be kept in the study database using your coded identification number. If you do not want to answer some of the questions on the questionnaires you do not have to but you can still be in the study. Your decision whether or not to be part of the study will not affect your continuing access to services at St. Joseph's Hospital.

How do I find out what was learned in this study?
I expect to have this study completed by approximately June 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you.



Who can I contact if I have questions about this study?
If you have any questions about the study, please contact me at: costal4@mcmaster.ca.
This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HIREB at 905-521-2100 ext. 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Lucia Costantini, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a copy of this form. I agree to participate in the study.

1. I would like to receive a summary of the study's results. Yes No

If yes, where would you like the results sent:

Email: ____________________________

Mailing address: ____________________
____
____
____

Name of Participant (Printed) ____________ Signature ____________ Date ____________

Consent form explained in person by :

Name and Role (Printed) ____________ Signature ____________ Date ____________

JUN 17 2014

Version #1 – June-9-2014

Page 3 of 3

Appendix E: Study Questionnaires (Phase Three)

Demographic Questionnaire

ID Number ________

1. Gender: ☐ 1 Male ☐ 2 Female

2. Birthdate ________ ________ ________
Month Day Year

3. What is the highest level of education you have obtained?

☐ 1 Grade School
☐ 2 High School or equivalent
☐ 3 Some/complete College
☐ 4 Some/complete University
☐ 5 Other (please specify) _________

4. What is your current relationship status?

☐ 1 Single
☐ 2 Married/Common-law/Partner
☐ 3 Separated
☐ 4 Divorced
☐ 5 Widowed

5. What is your current living situation?

☐ 1 Live alone
☐ 2 Spouse or partner
☐ 3 Family or friends
☐ 4 Roommate
☐ 5 Children
☐ 6 Other (please specify) _________

6. Do you have a caregiver to support you (For example, spouse, partner, family, friend, neighbor that accompanies you to appointments, helps you get groceries, or picks-up medications)?

☐ 1 Yes
☐ 2 No

7. What is your current employment status? (check all that apply)

☐ 1 Employed: ☐ 1A Full-time ☐ 1B Part-time/casual

☐ 2 Unemployed

☐ 3 Long-term disability

☐ 4 Student

☐ 5 Retired

☐ 6 Other (please specify) _______________

8. How much is your gross household income per year (before deductions of tax and other mandatory payments)?

☐ 1 less than $25 000

☐ 2 $25 000 to $50 000

☐ 3 $ 51 000 to $ 100 000

☐ 4 More than $ 100 000

☐ 5 Would prefer not to specify

9. What year were you first told by your physician that you have chronic kidney disease? __________

10. What year did you first start dialysis? _________

11. Do you have any other chronic illnesses?

☐ 1 No

☐ 2 Yes (check all that apply)

☐ 2-1 Heart disease ☐ 2-2 High Blood Pressure ☐ 2-3 High cholesterol

☐ 2-4 Stroke

☐ 2-5 Diabetes (☐ 2-5A Type I (insulin dependent) OR

☐ 2-5B Type II (non-insulin dependent)

☐ 2-6 Arthritis ☐ 2-7 Lung disease ☐ 2-8 Cancer

CONTINUE ON THE NEXT PAGE

☐2-9 Anxiety disorder
(Do you take medication for this condition ☐2-9A Yes ☐2-9B No)
(Have you received counseling for this condition ☐2-9C Yes ☐2-9D No)

☐2-10 Depression disorder
(Do you take medication for this condition ☐2-10A Yes ☐2-10B No)
(Have you received counseling for this condition ☐2-10C Yes ☐2-10D No)

☐2-11 Other (please specify) ____

ID Number ________

K10

For all questions, please fill in the appropriate response.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. In the past 4 weeks, about how often did you feel tired out for no good reason?					
2. In the past 4 weeks, about how often did you feel nervous?					
3. In the past 4 weeks, about how often did you feel so nervous that nothing could calm you down?					
4. In the past 4 weeks, about how often did you feel hopeless?					
5. In the past 4 weeks, about how often did you feel restless or fidgety?					
6. In the past 4 weeks, about how often did you feel so restless you could not sit still?					
7. In the past 4 weeks, about how often did you feel depressed?					
8. In the past 4 weeks, about how often did you feel that everything was an effort?					
9. In the past 4 weeks, about how often did you feel so sad that nothing could cheer you up?					
10. In the past 4 weeks, about how often did you feel worthless?					

CISS:SSC

The Multi-Health Systems Inc., responsible for the publication of the CISS:SSC, granted permission for the reprinting of 6 instrument items outlined below.

1) Determine a course of action and follow it
2) Work to understand the situation
3) Blame myself for having gotten into the situation
4) Focus on my general inadequacies
5) Treat myself to a favorite food or snack
6) Phone a friend

Items are ranked on a 5-point Likert scale ranging from 1 "not at all" to 5 "very much" something that the person would do to deal with stress.

Self-Management

Consider how you have been managing your illness over **the past 4 weeks**. Please circle a number from 1 to 7 for each statement below.

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
1. I can figure out which symptoms tell me the most about my illness.	1	2	3	4	5	6	7
2. When I experience emotional symptoms (e.g. nervousness, sadness), I do things to help me feel able to manage.	1	2	3	4	5	6	7
3. I try to find ways that make my life as normal as possible.	1	2	3	4	5	6	7
4. I ask my health care providers (doctors, nurses, dieticians, pharmacist) for information about my illness.	1	2	3	4	5	6	7
5. I am comfortable telling my health care provider which treatment recommendations work best for me (e.g. how much fluid removal you can tolerate).	1	2	3	4	5	6	7
6. I pay attention to events in my every day life that may cause my illness to get worse.	1	2	3	4	5	6	7
7. When I experience body symptoms (e.g. tiredness, thirst), I do things to help me feel better (stay calm, try to relax, take medication for pain).	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
8. I try to be positive about my life in spite of my illness.	1	2	3	4	5	6	7
9. I ask my health care providers (doctors, nurses, dieticians, pharmacist) for information about my treatment.	1	2	3	4	5	6	7
10. I am comfortable talking to my health care provider about ways to change my care (diet, medications, body weight) to better fit with my every day life.	1	2	3	4	5	6	7
11. I pay attention to body signs and symptoms (e.g. difficulty breathing, chest pain, changes in body weight, blood sugar level).	1	2	3	4	5	6	7
12. I participate in my dialysis treatments (e.g. weigh myself, take my temperature, connect myself to the machine).	1	2	3	4	5	6	7
13. I figure out ways to fit my dialysis therapy into my everyday life.	1	2	3	4	5	6	7
14. I am comfortable talking to my health care providers about my illness.	1	2	3	4	5	6	7
15. I am comfortable asking others (family, friends, coworkers) for help with managing my illness.	1	2	3	4	5	6	7
16. I can usually figure out the reasons for changes of my symptoms (e.g. breathing, body weight, blood pressure, chest pain,	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
blood sugar levels).	1	2	3	4	5	6	7
17. I drink fluids as suggested by my health care providers.	1	2	3	4	5	6	7
18. I think of my dialysis treatments as a way to stay healthy.	1	2	3	4	5	6	7
19. I am comfortable talking to my health care providers about my treatment plan.	1	2	3	4	5	6	7
20. I look for information on the Internet about my illness and treatment.	1	2	3	4	5	6	7
21. I pay attention to how much weight I gain between dialysis treatments.	1	2	3	4	5	6	7
22. I do things to take care of my dialysis access site.	1	2	3	4	5	6	7
23. I think of my medical appointments (e.g. going to dialysis, medical appointments) as a chance to socialize with other people.	1	2	3	4	5	6	7
24. I talk to my health care providers to figure out ways to change my treatment plan when necessary.	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
25. I seek out written information about my illness and treatment.	1	2	3	4	5	6	7
26. I pay attention to how my dialysis treatment makes me feel (e.g. cramping, low blood pressure, nausea, vomiting).	1	2	3	4	5	6	7
27. I find ways to protect my dialysis access site.	1	2	3	4	5	6	7
28. I follow a routine that fits with my preferred lifestyle (e.g. eating, sleeping, work).	1	2	3	4	5	6	7
29. I talk to my health care provider about goals I would like to accomplish to improve my health.	1	2	3	4	5	6	7
30. I talk to other patients on dialysis for information about the illness and treatment.	1	2	3	4	5	6	7
31. I figure out ways to make sure that my dialysis access site is protected.	1	2	3	4	5	6	7
32. I keep a record of how much fluid I gain between dialysis treatments.	1	2	3	4	5	6	7
33. I adjust other responsibilities (e.g. work, household chores) in my life to fit with my dialysis treatment schedule.	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
34. I talk to my health care provider to figure out ways to manage my symptoms (e.g. shortness of breath, chest discomfort, blood sugar, fatigue, depression).	1	2	3	4	5	6	7
35. When necessary, I figure out other ways to get the care I need.	1	2	3	4	5	6	7
36. I pay attention to the foods I choose to eat.	1	2	3	4	5	6	7
37. I keep a record of my blood pressure readings.	1	2	3	4	5	6	7
38. I change how much fluids I drink to fit with my everyday life.	1	2	3	4	5	6	7
39. I participate in making decisions about my treatment plan.	1	2	3	4	5	6	7
40. I look for alternative therapy experts (naturopathic doctor, acupuncture, etc.) to help me manage my illness.	1	2	3	4	5	6	7
41. I pay attention to my blood laboratory results (potassium, phosphorous, hemoglobin).	1	2	3	4	5	6	7
42. I take my medications as it has been prescribed for me.	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
43. I adjust my eating to fit with other activities (e.g. going to a party, restaurant).	1	2	3	4	5	6	7
44. I am comfortable talking to my health care providers about my test results (e.g. blood work, angiogram, x-rays).	1	2	3	4	5	6	7
45. I pay attention to my medications and how they make me feel.	1	2	3	4	5	6	7
46. I eat meals according to the recommended diet plan.	1	2	3	4	5	6	7
47. I can recognize when I need help from health care providers.	1	2	3	4	5	6	7
48. I ask my health care provider for help when I feel my illness is too hard to manage.	1	2	3	4	5	6	7
49. I can figure out ways to manage my fatigue.	1	2	3	4	5	6	7
50. I use alternative therapies (naturopathic doctor, acupuncture, etc.) to manage my illness.	1	2	3	4	5	6	7
51. I pay attention to how I am feeling emotionally (e.g. tired, frustrated, angry, depressed).	1	2	3	4	5	6	7

	1 **Never**	**2** **Rarely** (less than 10% of the time)	**3** **Occasionally** (30% of the time)	**4** **Sometimes** (50% of the time)	**5** **Frequently** (70% of the time)	**6** **Usually** (90% of the time)	**7** **Always**
52. I ask for help from health care providers when I need it.	1	2	3	4	5	6	7
53. I alter my medication schedule to fit with other areas of life (e.g. socializing, work).	1	2	3	4	5	6	7