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A MEASURE OF NEPHROLOGY NURSE PERCEPTIONS TOWARD ADVANCE CARE PLANNING:
VALIDATION OF THE NEPHRN PERCEPTIONS TOWARD
ADVANCE CARE PLANNING INSTRUMENT

Mary S. Haras

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This dissertation is a report of a three-phase quantitative research study that included the development and testing of an instrument to examine the perceptions of nephrology nurses toward advance care planning for persons with chronic kidney disease. Phase 1 began with the identification of the dimensions of advance care planning and creation of an item pool for the instrument. The instrument was distributed to five content experts for evaluation and comments of inclusiveness to measure perceptions toward advance care planning. In Phase 2 the item pool was pilot tested in a convenience sample of 50 nephrology nurses. Exploratory factor analysis using principal component analysis determined four factors that accounted for the variation among the latent variable of advance care planning. The 30-item instrument explained 64% of model variance and had strong internal reliability consistency for the scale and each subscale. In Phase 3 the instrument was tested in a convenience sample of 230 nephrology nurses contacted primarily via mailed postcards or professional networking sites with the web address to access the survey. Confirmatory factor analysis supported the four distinct dimensions of the newly developed instrument to measure nephrology nurse perceptions toward advance care planning. Construct validity of the NephRN Perceptions toward Advance

Care Planning instrument was determined through correlation analysis with the Concerns about Dying scale and the Attitude toward Patient Advocacy scale. The final 12-item NephRN Perceptions toward Advance Care Planning instrument had strong internal reliability consistency.

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MARY S. HARAS

A Dissertation Submitted in Partial
Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

Mennonite College of Nursing

ILLINOIS STATE UNIVERSITY

2014

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ADVANCE CARE PLANNING INSTRUMENT

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CHAPTER I
EXPLORING ADVANCE CARE PLANNING FROM THE
NEPHROLOGY NURSE PERSPECTIVE

Abstract

Advance care planning is a process that engages healthcare providers and patients to articulate the patient's wishes as their illness progresses. Persons with chronic kidney disease require earlier and more frequent advance care planning conversations because they are faced with increased co-morbidities and a shortened lifespan. This literature review will explore the phenomenon of advance care planning and the potential factors affecting nephrology nurse engagement in these discussions.

Chronic kidney disease (CKD) is a progressive, debilitating condition that is known to significantly shorten the lifespan of those affected (U.S. Renal Data System [USRDS], 2012). Because these individuals have a higher risk of early death, palliative care services and earlier discussion of advance care planning to maintain an optimal quality death trajectory are necessary (Brown, 2007; Noble, 2008; Robert Wood Johnson Foundation, 2003). Mortality rates for persons with CKD are approximately 59% higher than among those without CKD (USRDS, 2012). Over the past decade or so, the adjusted incident rate based on age, gender and race, of end-stage renal disease (ESRD) has grown nearly 12% for patients age 75 and older (USRDS, 2012), with the highest mortality rates within the first two months of initiating hemodialysis (USRDS, 2012). For the patient with ESRD, 96% will die within one month of discontinuing dialysis and would benefit from hospice and palliative care services (Thompson, Bhargava, Bachelder, Bova-Collis, & Moss, 2008).

Typically, less than half of the individuals with CKD have completed advance directives (Davison, 2009; Wilkinson, Wenger, & Shugarman, 2007), and to date, no data exist identifying the number of these individuals who participate in advance care planning discussions (Davison, 2009). As the number of persons with CKD continue to grow, it is necessary to gain a more thorough understanding of the role of nephrology nurses with advance care planning to provide the highest level of end-of-life care.

Nephrology nurses care for patients in all stages of CKD and are poised to participate in and facilitate advance care planning discussions, yet nurse participation rates remain low (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996; Rabetoy & Bair, 2007, Yee et al., 2011). One of the earliest studies exploring nephrology nurse engagement found that nephrology nurses engage in advance care planning discussions with less than 25% of patients who would benefit from this intervention (Perry et al., 1996). Perry and colleagues (1996) reported that nurses

caring for patients on dialysis discussed advance directives much less often than did social workers (60%), physicians (38%), or licensed practical nurses (30%). Rabetoy and Bair (2007) found that social workers were more likely to discuss advance directives with patients with CKD than were nurses. Yee and colleagues (2011) found that only 37% of Singapore nephrology nurses viewed advance care planning discussions as part of their role. These nurses had the least amount of confidence and the greatest amount of fear in conducting advance care planning discussions as compared to other Singapore healthcare providers (Yee et al., 2011).

There are a number of important guidelines and recommendations related to quality end-of-life care and advance care planning to assist nephrology nurses in their daily practice as they deal with difficult end-of-life issues (Agency for Healthcare Research and Quality 2003; American Nephrology Nurses Association [ANNA], 2013; Robert Wood Johnson Foundation, 2003). For example, the ANNA *End-of-life Decision-Making and the Role of the Nephrology Nurse Module 1* (2013) provides specific techniques and examples to facilitate advance care planning discussions with patients and how to broach the subject with physicians in an easy-to-follow PowerPoint format. Despite these resources, nephrology nurses do not appear to be actively engaged in the process of advance care planning (Ceccarelli, Castner, & Haras, 2008; Perry et al., 1996; Rabetoy & Bair, 2007; Yee et al., 2011). This literature review will explore the phenomenon of advance care planning and why nephrology nurses are not actively engaged in these discussions.

Advance Care Planning

Advance care planning is an integral process in end-of-life care (Mularski et al., 2007) and encompasses much more than the completion of advance directives (Davison, 2009). Advance care planning is defined as an ongoing process that necessitates multiple discussions, clarification, and communication between the healthcare providers, the patient, and their family

members to achieve the outcome of identification of the values, treatment preferences, and goals, for care at the end of life (Black & Emmett, 2006; Bloomer, Tan, & Lee, 2010; Davison, 2009). For the patient with CKD, the definition of advance care planning is expanded to include discussions about the initiation or discontinuation of dialysis in their end-of-life care treatment decisions (Brown, 2007).

Advance care planning has many benefits for the patient and the family. A positive advance care planning experience can improve relationships and support the grief process after the patient's death (Kruthaup, 2006). Successful end-of-life discussions can facilitate a comfortable and peaceful death, rather than one that is uncomfortable and filled with suffering (Rosemeyer, 2008). Open discussions enable the patient and family time to say goodbye, choose the place of death, and access palliative care and hospice services that will promote a good death (Sedgewick, Noble, Ho, Kafka, & van Waelegem, 2010). Advance care plans support patient autonomy in decision-making (Calvin & Eriksen, 2006; Newton, Clark, & Ahlquist, 2009). Advance care planning discussions can inform patients and their families of the economic burden of life-sustaining treatments.

Advance care planning in general has been studied in discrete concepts in studies about health provider death anxiety (Ali & Ayoub, 2010), fear of death or dying (Dunn, Otten, & Stephens, 2005), attitude toward and predictors of advance directive discussions (Lipson, Hausman, Higgins, & Burant, 2004), and nurse autonomy related to caring for patients at the end of life (Miyashita et al., 2007). What is noteworthy about these studies is that they focused on determining factors that affect nurse attitudes about caring for dying patients or participating in advance directives completion and did not include nephrology nurses. Identifying nurse perceptions about the bigger picture of advance care planning is very different

from identifying nurse attitudes about caring for dying patients or participating in completion of advance directives.

Westley and Briggs (2004) recognized that nurses in general are in “an ideal position” (p. 11) to facilitate advance directives discussions because of their “prolonged and consistent exposure to patients, skill at therapeutic communication, and orientation toward patient advocacy” (p. 11). Although nurses may possess the skills to engage in advance care planning, nurses in general have difficulty to advocate for improved end-of-life care because they are torn between their own values and the demands of families, physicians, and the environment in which they work (Kerfoot, 2012). Without appropriate support from leadership to be able to provide end-of-life care, these nurses will experience stress, burnout, and ethical distress (Kerfoot, 2012).

Nephrology nurses are positioned to address end-of-life issues including advance care planning and have the resources to do so (ANNA, 2013; Rabetoy & Bair, 2007). Nephrology nurses however, have identified workplace barriers impacting their ability to provide quality patient care (Gardner & Walton, 2011; Thomas-Hawkins, Denno, Currier, & Wick, 2003). There is a gap however, between the assumption that nephrology nurses are the most appropriate healthcare providers to conduct advance care planning discussions and nurses actively participating in these discussions (Ceccarelli et al., 2008; Rabetoy & Bair, 2007).

Search Strategy

Two literature searches were conducted between September 2010 and November 2013 using the EBSCOhost Discovery Service that explored the following databases: Academic Search Complete, CINAHL, and Science Direct. The reference lists of selected articles were used to locate additional articles for this review.

First, general information about end-of-life care and advance care planning from the nursing perspective was sought from peer-reviewed articles published in English between 1990 and 2013. Prior to 1990, advance care planning was not a well-defined concept. Search terms included end-of-life, nurses, chronic illness, and advance care planning resulting in over 7,000 articles. The EBSCOhost Discovery Service provides the option to refine searches by a number of limiters, including language, geography, content provider, and a list of subjects categorized from the larger search. The search was refined using selected Subject Limiters. These limiters included nurses, nursing, end-of-life care, advance care planning, end of life, and chronic diseases, resulting in 726 articles. Further subject limiters of terminal care, palliative care, qualitative research, thematic analysis, research, and chronic illness were applied, reducing the list to 365 articles. Additional subject limiters of experience, end of life care, research-methodology, and advance directives-medical care were applied, reducing the list to 81. Following this, titles and abstracts were reviewed for applicability to the subject of advance care planning from the nurse perspective. Twelve research articles were found.

Second, a search was conducted that focused specifically on the role of the nephrology nurse in advance care planning. Search terms included advance care planning, nephrology nurse, and ACP. Inclusion criteria for the second search were that the article (a) specifically addressed the role of the nephrology nurse in advance care planning, (b) was published between 1990 and 2013, (c) was peer-reviewed, and (d) was reported in English. The search strategy resulted in the identification of 418 articles. The results were refined by applying Subject Limiters of nephrology nursing, advance care planning, research, chronic renal failure, end of life care, and nephrology, resulting in 65 articles. Duplicate entries were removed, resulting in 52 articles. Conference abstracts were excluded from review. Next, a title and abstract search was conducted for relevance to advance care planning and the role of the

nephrology nurse, which reduced the number to four research articles. The review of reference lists yielded an additional four articles; two each in nephrology and non-nephrology studies. Table 1 details the 20 research studies conducted in the nephrology and non-nephrology nurse populations related to end-of-life discussions. One article was an evidence-based project, 11 were qualitative studies, and eight were survey design studies. No literature reviews were found that examined nephrology nurse participation in advance care planning discussions.

Table 1
Review of Relevant Research Related to Advance Care Planning (ACP)

Reference/ Supporting Dimension	Purpose	Design	Sample/ Setting	Results	Strengths/ Limitations
Non-nephrology related studies					
Boddy et al., 2013 Knowledge Support Comfort	To understand perspectives of healthcare providers and patients in Australia about barriers to advance care planning	Qualitative Focus groups	N = 41 hospital practitioners; 10 Social workers, 7 Occupational Therapists, 4 Speech Therapists, 6 Physiotherapists, 4 dietitians, 7 Nurses, 3 physicians	Barriers in 3 major categories: Patient-centered, practitioner-centered, and system-centered. Lack of knowledge, lack of accessibility, timing of discussions, fears about mortality, confusion, sensitivity of practitioner related to own discomfort with death and dying, role uncertainty.	Strengths: Process and system barriers preventing ACP discussions in hospitals identified. Limitations: Majority of practitioners were social workers, only 7 of a possible 50 nurses participated.

				Awareness of the window of opportunity for discussions important.	
Colville & Kennedy, 2012	To explore views of nurses about advance care planning and the impact of an educational intervention about advance care planning	Qualitative, descriptive Interviews as follow-up to an educational intervention about advance care planning	Purposive sample (n = 6) Generalist and specialist nurses in hospital and community settings	Major themes identified: Knowledge communication skills, knowing when and how to initiate the discussion, nurses are an essential member of the healthcare team in regards to ACP.	Strengths: Educational programs raised awareness and participation in ACP discussions. Limitations: Small sample size, convenience sample.
Knowledge Attitude Comfort					
Gaudine et al., 2011	To understand the organizational ethical conflicts that hospital nurses experience in practice.	Qualitative descriptive Interviews	34 Registered nurses, 10 nurse managers, 31 physicians	Ethical conflicts related to not feeling valued, supported, or respected by organization, insufficient resources to conduct job, organizational policies conflict with personal values, lack of administrative support, and lack of organizational investment in nurse professional development.	Strengths: Role of administration important in conveying the values of the organization. Sufficiently large sample for qualitative study. Limitations: Healthcare providers in 2 hospitals in Canada.
Support					
Jeong et al., 2011	To identify the experiences of nurses with ACP and advance	Qualitative, Case-study design with participant observation and	N = 13 Registered Nurses caring for residents of long-term care facilities	ACP inhibited by lack of time, institutional culture, lack of knowledge. Nurses	Strengths: Described phenomenon of ACP in this setting. Limitations:
Knowledge Comfort Support					

	directives in Australia	interviews		uncomfortable with initiating discussions but wanted to be more involved in the process and were committed to EOL care.	Researcher bias. Halo effect.
Kayser-Jones et al., 2003	To examine the physical environment and organizational factors influencing process of care to terminally ill nursing home residents.	Qualitative, Participant observation, interviews	N = 35 Residents N = 52 Family members N = 66 Nursing staff N = 36 Physicians Reports 2 of 3 nursing homes	Physical environment inadequate for end-of-life care. Inadequate staffing and lack of supervision.	Strengths: Study identified support factors influencing adequate end-of-life care. Limitations: Small sample Quantitative studies needed re: staffing levels on outcomes.
Kinoshita & Miyashita, 2011	To develop an instrument to assess ICU nurse difficulties in providing EOL care in Japan	Survey design	N = 224 ICU nurses in 18 hospitals	5 factors identified in EFA: purpose of ICU, nursing system that allowed for adequate time and staffing, confidence in EOL care, caring for pts. and families at EOL, converting from curative to EOL care. Concurrent validity assessed with FATCOD-Japanese version and Nursing Job Stressor Scale.	Strengths: Identified 5 factors for difficulties in ICU nurses providing EOL care. Limitations: Small sample size. Low Cronbach's alpha for some of the subscales.

Lipson et al., 2004	To examine nurse knowledge, attitudes, experiences with AD and to examine predictors of AD discussions	Cross-sectional survey design	N = 719 Registered nurses in Ohio	Knowledge was positively correlated with AD discussions. Confidence in AD discussion skills was a significant predictor of AD discussions.	Strengths: Content validity established. Limitations: No Cronbach's alpha for entire instrument, and was .69 for attitude items. No factor analysis.
Macpherson et al., 2013	To explore views about ACP in persons with COPD	Qualitative, Grounded-theory interview/observation	N = 10 Persons with severe COPD in the UK	Pts wanted more discussion with healthcare professionals. ACP discussion should be ongoing and routinely offered.	Strengths: Patient focus confirmed desire for early discussions with healthcare providers and greater involvement in decision-making. Limitations: Only persons with severe COPD were interviewed. Ethnically similar respondents. Convenience sample less likely to be upset by discussion.
Putman-Casdorph et al., 2009	To determine nurse knowledge, attitude, confidence, and experiences with advance directive discussions	Survey design, using questions from Lipson et al.(2004) and author-designed questions	N = 87 Registered nurses from acute care hospital units	High on general knowledge questions but not on state-specific questions. Moderately negative attitudes toward advance directives, and moderately confident with ACP. Relationships between confidence and experience, $r =$	Strengths: Results similar to other studies, nurses lack knowledge and confidence. Limitations: Instrument not psychometrically tested. Sample was 1 hospital in the mid-Atlantic region of the US.

				.44, $p = .001$, confidence and nursing role, $r = .26$, $p = .01$, and experience and nursing role, $r = .43$, $p = .001$.	
Robinson et al., 2012	To explore healthcare provider attitudes about ACP for persons with dementia and palliative care	Qualitative, Focus groups	N = 18 Professionals (n = 7 nurses) in care areas for dementia and palliative care	Unsure of value of ACP even though had positive perceptions of it. Unclear role expectations. Unclear timing of ACP discussions. Adding ACP discussion as a quality indicator might negatively impact the ACP process.	Strengths: Experiences of a variety of providers sought. Limitations: Few RNs included in sample. No quantitative measure of knowledge and experiences.
Scherer et al., 2006	To measure knowledge of, attitude toward, and experiences with advance directives and end-of-life decisions of critical care nurses	Survey design Descriptive, correlational study	N = 210 Critical care nurses in New York State from AACN membership	Knowledge, Attitudinal, Experiential Survey on Advance Directives instrument = 115 items: subscales $\alpha = .58$ to $.95$. No scale α reported. Knowledge of advance directives differed by specialty certification. Attitudes about ADs were high, even if the patient wishes conflicted with those of the nurse. Level of	Strengths: Raised awareness of need for nurses to be patient advocate. Limitations: Low test-retest reliability for some scales, $r = .51$. Low internal consistency for attitude, $\alpha = .57$, experience with advance directives, $\alpha = .58$. Experience with EOL decision-making, $\alpha = .54$. Weak correlations between knowledge, confidence, age, and practice years (all $r < .31$, low response rate (20%).

				confidence in ADs differed by knowledge and perceived role in AD discussions. Lack of time to conduct discussions. Confidence correlated with education, $r = .18, p = .05$.	
Zhou et al., 2010	To establish reliability and validity of survey assessing oncology APN knowledge, attitudes, and practices to ACP	Descriptive, cross-sectional pilot survey design Items derived from previously developed instruments and author experience	N = 89 Oncology advance practice nurses	Knowledge was lacking about ACP, nurses had positive attitudes toward ACP. Staff discomfort was a major barrier to ACP discussions, time restraints were a common barrier. EFA yielded 5-factor solution. Cronbach's alpha .56 to .84. Higher-order factor analysis revealed a 2-factor solution accounted for 92.5% of total variance among all first-order factors.	Strengths: Psychometric testing conducted. Construct validity, content validity determined. Most common barriers were from patients and physicians. Limitations: Small sample size, social desirability bias, convenience sample.
Zomorodi & Lynn, 2010a	To explore definition of quality end-of-life care in the ICU	Qualitative, interview	N = 9 ICU nurses	Environmental factors such as noise and technology, and inadequate staffing negatively	Strengths: Identification of critical skills for nurses to possess. Limitation: Convenience
Knowledge Attitude Comfort Support					

influenced end-of-life care. sample, selection bias

Nephrology related studies

Axelsson et al., 2012	To describe thoughts and feelings about death and dying for persons on HD who are approaching end of life	Qualitative descriptive Interviews 31 interviews conducted over 12 months	N = 8 severely ill persons undergoing maintenance hemodialysis (5 men, 3 women) Age: 66 to 87 (M = 78) years Purposive sample 4 HD clinics in university setting, 2 satellite clinics in Sweden	3 main themes: Patients are aware of the imminence of death, adapt to that reality, and spend time thinking about their own death. Nurses need to be open to ACP discussions and have good communication skills.	Strengths: Raised awareness of barriers to provide existential support to patients to allow them to talk about their own impending death. Limitation: participants were included based on assessment of severe illness.
Calvin 2004	To explore end-of-life treatment decisions for persons on HD	Qualitative using grounded theory Interviews	N = 20 adult persons undergoing Hemodialysis (11 men, 9 women) Age: 34 to 80 (M = 55.8) years Purposive sample 3 HD units in central TX	Theory of personal preservation identified. Newly identified conceptualization of EOL decision-making process for persons on HD. Theory may help nurses improve communication	Strengths: New theory identified that recognizes "a higher force." Limitations: persons who were not as articulate could not adequately portray their perspectives.
Hopkins et al., 2011	To determine if EOL issues are a priority for the nephrology organization and how to	Evidence-based practice project Pre-/post-test	N = 18 Nephrology nurses N = 72 for follow-up survey for confidence	Educational intervention increased nurse knowledge, awareness of resources, and confidence in ACP	Strengths: Awareness of relationship between knowledge and confidence. Limitation: single

	assist patients with ESRD			discussions.	site EBP, generalizability of results.
Kirchhoff et al., 2012	To compare patient preferences for EOL care with care actually received at EOL	Qualitative, Randomized, stratified, post-test interview with patient and surrogate	N = 313 persons with CHF and ESRD and their surrogates	Pts and surrogates wanted to know why no one discussed ACP earlier with them. Staff reluctance should be reduced with training and time should be allotted for routine discussions.	Strengths: Intervention prompted continued discussion between patient and surrogates. Limitation: Only 1 state represented, mostly Caucasian. High death rate in sample.
Perry et al., 1996	To determine factors that might influence advance directives discussions in persons receiving HD	Survey design	N = 210 renal healthcare providers	Lack of knowledge and lack of training were most significant barriers to discussing advance directives.	Strengths: First study exploring end-of-life decision making in renal patients. Limitations: No psychometric testing of instrument.
Rabetoy & Bair, 2007	To increase nephrology nurse awareness of EOL issues for those on HD	Survey design	N = 50 Nephrology nurses	Knowledge of guidelines was less than 50%, nephrology nurses do not engage in ACP as often as other providers do. Limited significant findings: experience and beliefs about EOL care, p = .03. All other findings non-significant.	Strengths: Highlights available resources for nephrology nurses. Nurses and nephrologists need to increase their knowledge and comfort with EOL care. Limitations: Small sample size; Participants all members of specialty organization.

Yee et al., 2011	To explore knowledge, attitudes, and experiences of renal healthcare providers in Singapore about ACP for patients with ESRD	Survey design Items from Lipson et al. (2004) and Perry et al (1996) instruments	N = 560 (n = 461 nurses) Singapore health professionals	Nephrology nurses were less knowledgeable about ACP, more fearful of upsetting patients, did not perceive ACP as their role.	Strengths: Focuses on healthcare provider perspectives. Limitations: No psychometric testing of instrument; based on 2 instruments that also not psychometrically tested.
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Note: ACP = advance care planning; AD = advance directives; APN = advance practice nurse; EOL = end-of-life; ESRD = end-stage renal disease; HD = hemodialysis

Findings

Structural Dimensions

Knowledge of advance care planning. Knowledge and understanding of what advance care planning entails has been cited as nurse facilitators to advance care planning discussions (Boddy, Chenoweth, McLenna, & Daly, 2013; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2012; Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). From the general review of literature, determining the ‘window of opportunity’ also was deemed important (Boddy et al., 2013). This window of opportunity exists when the discussion of advance care planning is relevant to the patient and when the patient is able to participate in the discussion (Boddy et al., 2013). Several authors identified the relationship between knowledge of and comfort with conducting advance care planning discussions (Colville & Kennedy, 2012; MacPherson, Walshe, O’Donnell, & Vyas, 2013; Scherer, Jezewski, Graves, Wu, & Bu, 2006; Zhou et al., 2010).

From the review of literature about nephrology nurses, it was found that nephrology nurses lacked knowledge and training about advance directives (Perry et al., 1996). Rabetoy and Bair (2007) reported similar results and determined “nephrology nurses needed educational

assistance for developing programs addressing advanced care planning for patients (p. 602). Hopkins and colleagues (2011) concluded that an educational session about advance care planning for persons with renal disease significantly improved their knowledge about resources for advance care planning. Ceccarelli and colleagues (2008) suggested that nephrology nurses did not know when or how to initiate advance care planning discussions and that further formal research needs to be conducted with this population.

Support for advance care planning. Institutional supports in the form of an adequate physical environment (Kayser-Jones et al., 2003) and a supportive organizational culture (Jeong, Higgins, & McMillan, 2011) have been cited as facilitators to successful advance care planning. Strong organizational support and a supportive environment facilitate participation in end-of-life discussions (Zomorodi & Lynn, 2010a). Lack of organizational support contributed to feelings of ethical conflict in hospital nurses, and that these nurses viewed administrators as the face of the organizational values (Gaudine, LeFort, Lamb, & Thorne, 2011). Inadequate staffing was identified as a barrier to providing end-of-life discussions (Kinoshita & Miyashita, 2011). Time constraints were frequently identified as a barrier to advance care planning by nurses in a variety of settings (Macpherson et al., 2013; Zhou et al., 2010; Zomorodi & Lynn, 2010a).

A review of the nephrology nursing literature confirmed the need for organizational support when considering advance care planning discussions. Perry et al. (1996) identified a lack of support from physicians and supervisors. Knowledge and comfort for advance care planning discussions would improve if the organization provided training and allocated sufficient time for discussions (Kirchhoff et al., 2012). Resources to facilitate advance care planning discussions are readily available. Rabetoy and Bair (2007) summarized the Renal Physicians Association guidelines for shared decision-making and the ANNA ethics module on advance care planning

that are available to facilitate nephrology nurse knowledge and comfort with advance care planning discussions.

Procedural Dimensions

Attitude toward advance care planning. One's personal beliefs and prior experiences with advance care planning shape one's attitude toward participation in future advance care planning discussions (Lipson et al., 2004; Macpherson et al., 2013; Putman-Casdorph, Drenning, Richards, & Messenger, 2009; Robinson et al., 2012; Scherer et al., 2006; Zhou et al., 2010). Nurses' attitudes toward end-of-life care are shaped by personal, cultural, and prior professional experiences, affecting the way in which nurses relate to patients needing intervention at the end-of-life (Zomorodi & Lynn, 2010b). Boddy et al. (2013) and Zhou et al. (2010) reported barriers of ambivalence, uncertainty, and biased views about the benefits of advance care planning. Similarly, nurses caring for persons with dementia and palliative care needs reported uncertainty about the value or usefulness of advance care planning (Robinson et al., 2012). Many healthcare providers, including nurses, had positive feelings about initiating advance care planning, but were uncertain about how it could be implemented in their patient population (Robinson et al., 2012). Lipson et al. (2004) reported nurse confidence in discussing advance directives was a significant predictor of their likelihood to engage in these discussions.

Nephrology nurses generally were in favor of advance care planning and recognized the potential benefits of these discussions (Yee et al., 2011). These nurses however, were more "concerned about the potential negative impact of advance care planning discussions on patients and families" (Yee et al., 2011, p. 234). These potential negative impacts included worrying about upsetting the patient, making the patient lose hope, and causing the family to blame the nurse for patient choices (Yee et al., 2011). Ceccarelli and colleagues (2008) found similar negative attitudes toward advance care planning; nurses indicated fear of upsetting the

patient and negative family reactions to the discussions. Understanding patient attitudes and motivators to discuss advance care planning may help nurses improve their communication with patients and families about advance care planning (Calvin, 2004).

Nurse comfort with advance care planning discussions. Prior experiences with death and dying established nurses' level of comfort in caring for dying patients (Caton & Klemm, 2006). Educational programs about advance care planning validated the knowledge and skills of community health nurses, increasing nurse comfort and confidence in conducting these discussions (Colville & Kennedy, 2012). ICU nurses were increasingly comfortable with end-of-life care the more they were exposed to it in practice (Zomorodi & Lynn, 2010a). Nurses were moderately confident in their advance directives discussion skills, and nurses who had more exposure either in nursing school or in practice had statistically significant differences in their advance directives discussions than those who did not have that exposure (Lipson et al., 2004). The greater nurses' confidence in advance care planning discussion skills, the greater the likelihood nurses were to participate in advance directive discussions (Lipson et al., 2004). Staff nurse discomfort with the advance care planning process was derived from nurses' general discomfort with death and dying or from their belief that advance care planning is not their role (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Since advance directives are one component of advance care planning, nurses who are confident with advance directive discussions may also be comfortable with advance care planning discussions.

Nurses' perception of their autonomy and role in patient advocacy is a significant factor in determining how comfortable the nurse feels in conducting advance care planning discussions. Patient advocacy as a mid-range theory was proposed by Bu and Jezewski (2007) and includes acting on behalf of the patient and safeguarding patient autonomy. Patients were positively influenced by nurses who consistently scored higher on the Attitude toward Patient

Advocacy scale (Bu & Wu, 2008), supporting Bu and Jezewski's (2007) theory that patient advocacy is an important concept in the perceived role of the nurse.

From the review of literature about the nephrology nurse perspective, Tigert, Chaloner, Scarr, and Webster, (2005) noted the difficulty in initiating advance care planning discussions because of the comfort level of the healthcare team, particularly in relation to their comfort with death and dying. Nephrology nurse barriers to advance care planning include not viewing advance care planning as a nursing responsibility and being fearful of upsetting the patient (Yee et al., 2011). Nurse comfort with advance care planning must increase in order to provide quality end-of-life care (Rabetoy & Bair, 2007). Nurses need to be open to advance care planning discussions and have good communication skills to be able to do so (Axelsson, Randers, Hagelin, Jacobson, & Klang, 2012). Ceccarelli and colleagues (2008) found nurses lacked confidence in starting the conversation about advance care planning, thus affecting their comfort level with these discussions. Part of their lack of confidence stemmed from inadequate knowledge or lack of resources about advance care planning (Ceccarelli et al., 2008).

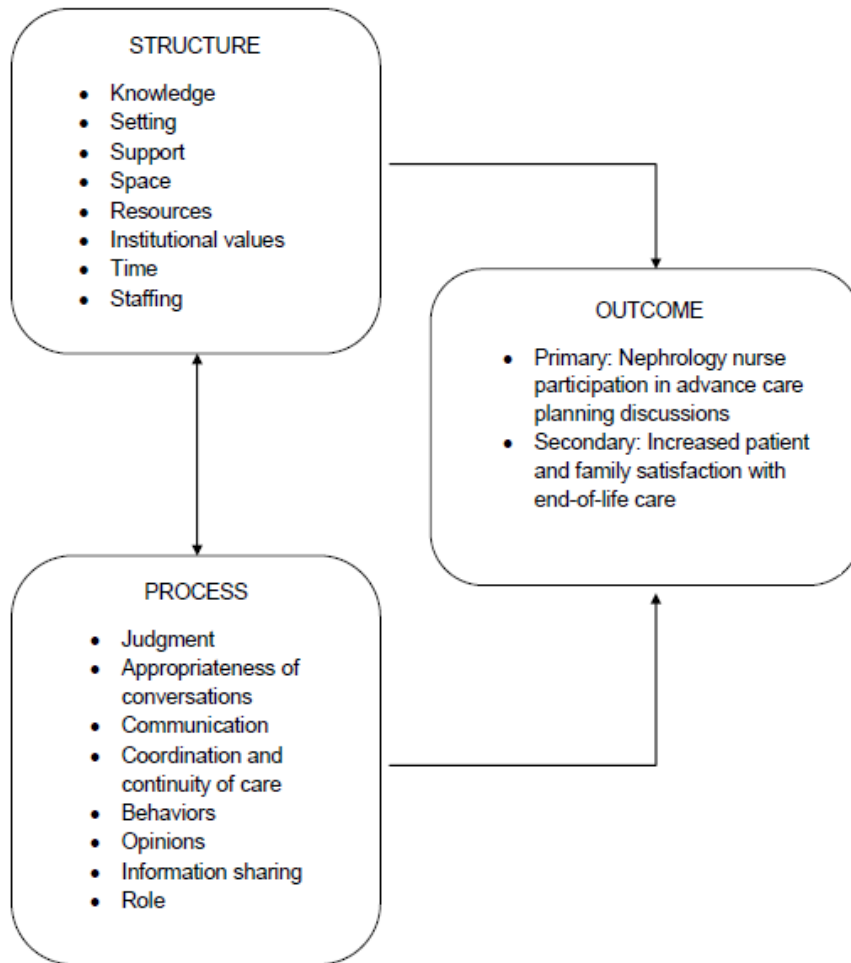
Discussion

Stewart, Teno, Patrick and Lynn (1999) developed a detailed conceptual model of quality and outcomes of care for terminally ill individuals following an extensive review of the literature and based on proposed domains from the American Geriatrics Society 1996 clinical practice committee. This conceptual model identified elements of structure of care, process of care, and satisfaction with care. Structural components of advance care planning include social support, institutional values and mission, organizational structure, time, staffing, and resources (Stewart et al., 1999). Procedural components are directly related to completing the advance care planning process; knowledge and information sharing, and skills related to communication, technical, affective, and patient-centered approach to provision of care (Stewart et al., 1999).

Four structural and procedural dimensions of the advance care planning process can be summarized from this thematic review of literature: knowledge, support, attitude, and comfort.

Figure 1 depicts the conceptual framework for this study, based on Stewart et al., (1999) structure-process-outcome quality model.

Figure 1. Depiction of Structure and Process Components Affecting the Outcome of Successful Advance Care Planning.



Adapted from “The Concept of Quality of Life of Dying Persons in the Context of Healthcare,” by A. L. Stewart, J. Teno, D. L. Patrick, and J. Lynn, 1999, *Journal of Pain and Symptom Management*, 17, p. 96. Copyright 1999 by U.S. Cancer Pain Relief Committee.

The growing health problem of advancing CKD is receiving more attention since the passage of the Patient Self Determination Act of 1990 (United States General Accounting Office, 1995). This necessitates a greater focus on early advance care planning for persons with CKD because of the significant personal and financial implications of this disease process. Nephrology nurses are poised to facilitate these discussions, but are reluctant to do so. Furthermore, there is a dearth of research to quantify the perceived barriers to nephrology nurse participation in this process.

This literature review helped to identify some structure and process components that may be necessary to increase nephrology nurse involvement in advance care planning. The literature about the role of nephrology nurses in advance care planning discussions suggests that advance care planning should be a priority in end-of-life care. Despite available resources to assist nephrology nurses in conducting advance care planning discussions (Haras, 2008; Price, 2003; Rabetoy & Bair, 2007), nephrology nurses are uncomfortable with this process and do not view participation in advance care planning discussions as part of their role (Ceccarelli et al., 2008; Hopkins et al., 2011; Rosemeyer, 2008; Yee et al., 2011). Nurses in general want to provide excellent end-of-life care, and nephrology nurses are no different. Persons with ESRD can remain on dialysis for years to decades, depending on the cause of their renal failure. The relationship and trust that develops between the nephrology nurse and the patients and families for whom they care positions nephrology nurses to facilitate advance care planning discussions.

Conclusion

It is apparent patients with CKD and their families need and want to hear realistic information about their prognosis (Kirchhoff et al., 2012). Nephrology nurses have historically not perceived having discussions about advance care planning as their role, typically deferring this responsibility to social workers and physicians, despite the trust that patients have in the

nephrology nurse. Current researchers have attempted to identify factors affecting nurse participation in advance care planning discussions. More studies are needed to evaluate nurses' knowledge, attitudes, confidence, and support for advance directives or advance care planning (Ceccarelli et al., 2008; Jeong et al., 2011; Putman-Casdorph et al., 2009; Zhou et al., 2010). The findings may suggest important dimensions of advance care planning that require further investigation. Through future studies, it may be possible to determine the factors that affect nephrology nurses' active participation in advance care planning and devise strategies to remove these potential barriers.

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CHAPTER II
DEVELOPMENT AND INITIAL VALIDATION OF THE NEPHRN PERCEPTIONS
TOWARD ADVANCE CARE PLANNING INSTRUMENT

Abstract

To promote a quality dying experience for persons with chronic kidney disease, it is important to understand why nephrology nurses are the least involved healthcare professionals in the advance care planning process despite being the most appropriate persons to do so. The purpose of this study was to develop and pilot test an instrument to identify nephrology nurse perceptions toward advance care planning. The newly developed NephRN Perceptions Toward Advance Care Planning instrument had strong item and instrument content validity indices. Four components of advance care planning were identified: Knowledge, Attitudes, Comfort, and Support. The 4-component solution explained 63.88% of variance. Cronbach's alpha was .92 and subscale reliability ranged between .86 and .94. This instrument shows promise as a reliable and valid measure of nephrology nurse perceptions toward advance care planning for persons with chronic kidney disease.

Key Words: advance care planning, instrument development; nephrology nurses, factor analysis, measurement

Individuals with advancing stages of chronic kidney disease (CKD), especially those at end-stage with less than 15% kidney function (Stage 5), have more co-morbidities and a life expectancy that is shortened by four to eight years compared to those without CKD (United States Renal Data System, 2012). Studies show that patients with end-stage renal disease (ESRD) undergoing hemodialysis want to discuss their end-of-life needs with their healthcare providers (Kataoka-Yahiro, Conde, Wong, Page, & Peller, 2010; Mohlzan et al., 2012), yet completion rates for advance directives remain low (Davison, 2009; Rabetoy & Bair, 2007). Advance care planning is necessary because it can open lines of communication between the patient and family allowing for much-needed dialogue about where the patient wants to die, types of end-of-life services the patient desires, and time for the family to say goodbye to the patient (Sedgewick, Noble, Ho, Kafkia, & van Waelegem, 2010). Advance care planning is a process that necessitates multiple discussions, clarification, and communication between the healthcare providers, the patient, and their family members to achieve the outcome of clarification and identification of the values, treatment preferences, and goals for end-of-life care (Davison, 2009). For the patient with ESRD, advance care planning is the formal process of “enabling patients to make treatment decisions about whether to start or stop dialysis and about end of life management” (Brown, 2007, p. 1250).

Because of the chronic and progressive nature of kidney disease, nephrology nurses develop long-term relationships with their patients and are in a position to conduct advance care planning discussions. The American Nephrology Nurses Association (2013) developed extensive modules to facilitate advance care planning discussions with patients and developed sample scripts for nurses to use in conversations with physicians about advance care planning. Yet, nephrology nurses are the least involved group of healthcare providers in facilitating advance care planning discussions (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996;

Rabetoy & Bair, 2007; Yee et al., 2011). It is therefore necessary to explore the factors that may be interfering with nephrology nurses' ability to engage in advance care planning with patients with CKD.

Conceptual Framework

Advance care planning is a complex phenomenon that requires the nurse to have key skills and support to be able to engage in advance care planning with patients and their families. The Donabedian (1966) structure-process-outcome quality model is a framework that focuses on identification of the structures and processes necessary to achieve high quality outcomes of care. Donabedian (1966) suggested identifying perceptions, knowledge, behaviors, and opinions that affect quality care rather than using empirical outcomes when measuring complex phenomena. For example, examining advance directives completion rates alone may not be a useful measure of quality end-of-life patient care. Examining nurse perceptions toward advance care planning may illuminate factors impeding nurse involvement in advance care planning. According to Donabedian (1966), "before one can make judgments about quality, one needs to understand how patients and [nurses] interact and how [nurses] function in the process of providing care" (p. 193).

In this study, structure and process elements affecting nephrology nurses' engagement in advance care planning were examined. For example, the structure of care is affected by the values and mission of the organization, the values of leadership and management, the allocation of time, and the availability of resources and adequately trained staff (Stewart, Teno, Patrick, & Lynn, 1999). The process of care is affected by the timeliness of the advance care planning discussion, the attitude of staff caring for the dying patient, the involvement of the patient and family in the decision-making process, and the ease in which the staff facilitate open communication between the patient and their loved ones (Stewart et al., 1999).

Review of Literature

Factors Related to Structure

Knowledge of advance care planning. Knowledge about advance care planning and knowing when to have the conversation is essential to determine nurse engagement in this process (Boddy, Chenoweth, McLenna, & Daly, 2013; Ceccarelli, Castner, & Haras, 2008; Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). Focus groups conducted by Boddy and colleagues (2013) identified lack of knowledge about advance care planning as the most significant healthcare practitioner barrier to the advance care planning process. Oncology nurses (Zhou et al., 2010) and generalist and specialist hospital nurses (Colville & Kennedy, 2012) reported that knowledge and confidence increased after educational interventions about advance directives and advance care planning. Lack of knowledge and training were the most significant barriers to nurses discussing advance directives with persons receiving hemodialysis (Perry et al., 1996).

Support for advance care planning. Organizational support for nurses is essential to promote nurse engagement in advance care planning (Kayser-Jones et al., 2003; Kinoshita & Miyashita, 2011). In the physical environment, "inadequate staffing and lack of supervision were among the most significant organizational factors that influenced care" (Kayser-Jones et al., 2003, p. 76). In nephrology nurses, Perry and colleagues (1996) identified "lack of support from supervisory and physician staff within the dialysis team" (p. 2160) as a significant barrier to advance directives discussions. Ceccarelli and colleagues (2008) reported that nephrology nurses were unsure of the support they would receive from supervisors, peers, and physicians regarding advance care planning discussions. In a workplace satisfaction study, Thomas-Hawkins, Denno, Currier, and Wick (2003) found nephrology nurses perceived inadequate orientation programs and work environments that did not support nurse participation in patient

care or did not value nurses. Gardner and Walton (2011) confirmed the importance of a positive work environment in their study of nurses in outpatient dialysis facilities.

Factors Related to Process

Attitude toward advance care planning. Attitudes toward death and dying, advance directives, and advance care planning are important predictors of nurse participation in advance care planning discussions (Caton & Klemm, 2006; Lipson, Hausman, Higgins, & Burant, 2004; Robinson et al., 2012; Zhou et al., 2010). Oncology nurses' prior experiences with dying patients shaped their attitudes about the dying process and mentors or clinical preceptors were suggested to provide emotional support to the novice nurses (Caton & Klemm, 2006). Midwestern registered nurses generally had very positive attitudes toward advance directives, which correlated with their participation in advance directives discussions (Lipson et al., 2004). Nurses working with patients with dementia and palliative care needs generally reported positive attitudes about the benefits of advance care planning yet were ambivalent about their ability to carry out this function (Robinson et al., 2012). Yee and colleagues (2011) reported that nephrology nurses were "more concerned about the potential negative impact of advance care planning discussions on patients and families" (p. 234), but recognized the potential benefits of these discussions. Ceccarelli and colleagues (2008) also concluded that nephrology nurses were afraid of upsetting patients or family, affecting their likelihood to participate in advance care planning discussions.

Comfort with advance care planning. Closely tied with attitude toward advance care planning is comfort and confidence in conducting advance care planning discussions (Caton & Klemm, 2006; Colville & Kennedy, 2012; Lipson et al., 2004; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Oncology nurses' prior experiences with death and dying determined their level of comfort in caring for dying patients (Caton & Klemm, 2006).

Educational programs about advance care planning increased nurse comfort and confidence in conducting these discussions (Colville & Kennedy, 2012). Nurse comfort with advance directives was directly related to the amount of educational or practice exposure to advance directives (Lipson et al., 2004) Staff nurse discomfort with advance care planning was related to nurses' general discomfort with death and dying or from their belief that advance care planning was not their role (Schulman-Green et al., 2005).

Autonomy and patient advocacy are two concepts that are directly related to nurse comfort in advance care planning (Bu & Jezewski, 2007; Thacker, 2008). Patients were positively influenced by nurses who had a strong sense of patient advocacy (Bu & Jezewski, 2007). Thacker (2008) identified the importance of patient teaching as a form of patient advocacy. Despite having the knowledge about advance care planning, Thacker (2008) found three barriers to practicing advocacy: "the physician, the patient's family, and fear" (p. 179). In nephrology nurses, comfort in advance care planning discussions was related to nurse comfort with death and dying (Tigert, Chaloner, Scarr, & Webster, 2005). Nephrology nurses did not view advance care planning as their role, so were less comfortable participating in these discussions (Yee et al., 2011). In addition, nephrology nurses lacked confidence in starting advance care planning discussions, directly affecting their comfort with this process (Ceccarelli et al., 2008).

Existing Measures of Advance Care Planning

At least 10 instruments exist that measure related aspects of advance care planning, including healthcare provider concerns about dying (Mazor, Schwartz, & Rogers, 2004), fear of death or dying (Lester & Abdel-Khalek, 2003), attitudes toward death (Wong, Reker, & Gesser, 1994), attitudes toward caring for dying patients (Frommelt, 2003), and knowledge about advance directives (Duke & Thompson, 2007; Lipson et al., 2004). No psychometrically sound measures were found to assess nephrology nurse perceptions toward advance care planning. To

explore the predictors of nurse-initiated advance care planning discussions, researchers have often combined various measures to meet their needs (Lipson et al., 2004), or have designed their own measures (Jarr, Henderson, & Henley, 1998).

Assessing Attitudes

Perhaps the most widely used instruments are those related to attitudes and concerns of healthcare providers about death and dying. These measures however, do not measure nephrology nurse perceptions toward advance care planning. The 1988 Frommelt Attitude toward the Care of the Dying Scale (Frommelt, 1991), revised in 2003 (Frommelt, 2003) has been used extensively in healthcare and is based on Kubler-Ross' (1969) five stages of death and dying. This measure was developed to evaluate the effectiveness of a death education teaching intervention for nurses (Frommelt, 1991). Item content validity was 1.0, and Pearson's correlation coefficient was .94.

The Collett-Lester Fear of Death and Dying Scale (Lester & Abdel-Khalek, 2003) measures four separate fears: death of self, death of others, dying of self, and dying of others. This scale has undergone several revisions, and in version 3.0, has 28 items in four subscales (7 items each). Cronbach's alpha for each of the subscales range from .88 to .92, and item-total correlations were greater than .47 (Lester & Abdel-Khalek, 2003).

The Death Attitude Profile (Gesser, Wong, & Reker, 1987) was the first measure of four constructs of death attitudes in one scale: fear of death/dying, neutral acceptance, approach acceptance, and escape acceptance. The Death Attitude Profile-Revised (Wong et al., 1994) added a fifth dimension of assessing death attitudes, death avoidance. The initial Death Attitude Profile tested reliability and validity for 23 items across five categories (Gesser et al., 1987). Item-total and factor analyses were used to test internal consistency, and principal component factor analysis with varimax rotation was used to determine the multidimensionality of the

instrument. Face validity was assessed by asking end-users to categorize the statements into one of the five categories. Of the original 23 items, 21 were retained, which explained 51.6 % of variance. Rather than using Cronbach's alpha, Armor's Theta was used to determine reliability, and results suggested "fair to good internal consistency" (p. 119). After factor analysis and rotation, a four-factor model was retained (Gesser et al., 1987).

The Concerns About Dying Scale (Mazor et al., 2004) was developed to assess end-of-life concerns of healthcare providers. The Concerns About Dying Scale specifically assesses healthcare provider concerns about death and dying in general, spirituality, and concerns about patient-related death and dying (Mazor et al., 2004) and will be discussed in greater detail in the Instruments section of this manuscript.

Assessing Knowledge, Attitudes, and Comfort

Zhou and colleagues (2010) developed and tested an instrument with 89 oncology advance practice nurses to assess and understand oncology nurses' knowledge, attitudes, practices, and barriers to advance care planning. Exploratory factor analysis revealed a 5-factor solution with moderate to good internal consistency reliability: practice behaviors ($r = .83$), comfort level in discussing advance care planning ($r = .84$), nurse's professional responsibility in discussing advance care planning ($r = .76$), attitudes about meeting patient and family needs ($r = .72$), and attitudes about advance care planning and patient responses ($r = .56$; Zhou et al., 2010). This instrument was specific to oncology nurses and did not assess managerial or environmental support for advance care planning.

Lipson and colleagues (2004) developed a 52-item instrument to describe the knowledge, attitudes, and predictors of advance directives discussions of registered nurses. This instrument was created from three existing measures. Content validity was determined with eight content experts. No psychometric testing was conducted for this instrument (Lipson et al.,

2004). The instrument contained demographic questions in addition to questions about knowledge, attitude, and exposure to advance directives questions. Cronbach's alpha for the attitude items was .69 (Lipson et al., 2004). No other Cronbach's alpha scores were reported.

One instrument that focused on nephrology health providers measured the knowledge, attitudes, and experiences about advance care planning for persons with CKD (Yee et al., 2011). Questions for this instrument were adapted from the Update on Advance Directives questionnaire (Duke & Thompson, 2007) and the 52-item unnamed questionnaire by Lipson and colleagues (2004). No psychometric testing was conducted for this instrument (A. Yee, personal communication, January 30, 2012), but it is the most comprehensive measure found to assess nephrology nurse perceptions toward advance care planning. Perceived support for advance care planning however was not measured by this instrument.

Assessing Support

No instruments were found that assessed general or nephrology nurse support for providing advance care planning discussions. Gardner and Walton (2011) and Thomas-Hawkins and colleagues (2003) however, determined that it is important to assess factors that support nephrology nurses in their ability to conduct advance care planning discussions with persons with chronic kidney disease.

Purpose

Addressing the factors influencing nephrology nurse participation in advance care planning discussions will require a deeper understanding of nephrology nurse perceptions and attitudes. To date, no single instrument has been found that measures the nephrology nurse perceptions of knowledge, attitude, comfort, and support toward advance care planning. The purpose of this exploratory study was to develop and pilot test an instrument to measure nephrology nurse perceptions toward advance care planning. The research question is: Can we

measure advance care planning perceptions of nephrology nurses with adequate reliability and interpret scores with validity?

Methods

The instrument development was conducted in two phases following the guidelines for scale development identified by DeVellis (1991). Phase 1 consisted of reviewing the literature to identify the dimensions of advance care planning, generating the item pool, determining the measurement format, and having the item pool reviewed by content experts. Phase 2 consisted of administering the items in the newly developed NephRN Perceptions Toward Advance Care Planning instrument to a convenience sample of 50 nephrology nurses, evaluating the items' performance, and optimizing scale length.

Phase 1: Instrument Development

Dimensions of Advance Care Planning

A review of the literature identified factors affecting advance care planning discussions. These include lack of knowledge (Boddy et al., 2013; Perry et al., 1996; Rabetoy & Bair, 2007; Yee et al., 2011; Zhou et al., 2010), an unsupportive environment (Davison, 2012; Zomorodi & Lynn, 2010), unclear role expectations (Yee et al., 2011), a lack of skills or confidence to carry out the process (Ceccarelli et al., 2008; Colville & Kennedy, 2012; Lipson et al., 2004), a lack of administrative support (Ceccarelli et al., 2008; Kayser-Jones et al., 2003; Perry et al., 1996), inadequate staffing (Kayser-Jones et al., 2003; Kinoshita & Miyashita, 2011), and fear of upsetting the patient (Ceccarelli et al., 2008; Yee et al., 2011). These findings can readily be subsumed into the four dimensions identified for this study: knowledge, attitude, comfort, and support for advance care planning.

Item Development

Items for the NephRN Perceptions Toward Advance Care Planning instrument were developed to be congruent with the four dimensions of knowledge, attitude, comfort, and support that were identified from a review of existing literature, author experience with advance care planning, and feedback from the content experts. The initial NephRN Perceptions Toward Advance Care Planning instrument contained 53 items and was written at the 8.1 Flesch-Kincaid Grade Level, which is appropriate for professional workers and most instruments (DeVellis, 1991).

In the knowledge domain, participants were asked to indicate their agreement with statements about their overall knowledge about advance care planning and their preparation for advance care planning discussions. The items included defining and explaining advance care planning, knowing about appropriate resources for advance care planning, having formal education about advance care planning, and having the necessary skills to discuss advance care planning. In the attitude domain, participants were asked to indicate their agreement with statements about the positive and negative attitudes about advance care planning and the impact of these discussions. The items were specific to the nurses' perceptions of the positive and negative aspects of advance care planning. In the comfort domain, participants were asked to indicate their agreement with statements about the role of nurses in carrying out advance care planning discussions. The items included personal comfort with advance care planning and end-of-life issues, patient advocacy, and role responsibility. In the support domain, participants were asked to indicate their agreement with statements about how supported they felt by administration and colleagues. The items included managerial, peer, and physician support, workload adjustment, environmental considerations, and policies related to advance care planning discussions.

Determining Content Validity

The item pool in the NephRN Perceptions Toward Advance Care Planning instrument was reviewed by five content expert nurses with experience in at least two of the following areas; end-of-life, nephrology, research, and instrument design. The content experts were from various regions of the United States, had each been in practice for over 25 years, and had published research in their areas of expertise. One nurse had extensive experience in end-of-life care, research, and instrument design. Two nurses had extensive experience in nephrology, research, and end-of-life care. One nurse had extensive experience in research and instrument design. One nurse had extensive experience in end-of-life care and research. Four of the five had a PhD in nursing, and one had a Master's degree in nursing and is an advanced practice nurse currently working with persons with CKD.

Content experts received an e-mail with the instrument and instructions on how to evaluate the relevance, clarity, and conciseness of each item (DeVellis, 1991). Content experts rated each item on a 4-point Likert-type scale (1= *not relevant*, 2 = *somewhat relevant*, 3 = *quite relevant*, and 4 = *very relevant*) for its relevance to advance care planning and applicability in the nephrology nursing population (Grant & Davis, 1997). Content experts then categorized each item to one of the four advance care planning dimensions. When experts were unable to categorize an item they were asked to comment why they were unable to do so. Content experts also provided feedback on potential items that may have been overlooked (DeVellis, 1991).

The content experts indicated instrument items were reflective and inclusive of advance care planning, with item-content validity indices between .75 and 1.0, and an overall instrument validity index of .95. Inter-rater agreement was .77, well within the acceptable limits of .70-.80 (Grant & Davis, 1997). Five items were duplicate questions and were deleted from the

instrument. One additional item was added to the attitude dimension for pilot testing based on content expert feedback, resulting in a 48-item instrument.

Phase 2: Pilot Testing and Initial Psychometric Evaluation

The purpose of this phase of the study was to administer the 48 items in the NephRN Perceptions Toward Advance Care Planning instrument to a sample of nephrology nurses and then evaluate the performance of each item (DeVellis, 1991). This study was approved by the University Institutional Review Board prior to data collection.

Sample

A convenience sample of 30 nephrology registered nurses was recruited by an e-mail request to participate in the study; snowball sampling was used to recruit an additional 20 nephrology registered nurses. The final sample included 50 U.S. registered nurses with experience in caring for patients with CKD. The majority were female (91%), Caucasian (97.7%) and practiced in an outpatient setting (58%). Six participants did not identify their gender. The age of the participants ranged from 32 to 66 years ($M = 54.39$, $SD = 6.72$). Participants' experience as a nurse ranged from 11 to 46 years ($M = 30.49$, $SD = 7.75$); experience in nephrology ranged from 0 to 45 years ($M = 20.08$, $SD = 13.09$). Just over half of the respondents (54.5%) indicated they had a formal course related to death and dying since becoming a nurse and 75% had experience with advance care planning discussions with persons with CKD, averaging four to five times per year.

Instruments

Participants completed the 10-item Concerns About Dying Scale (Mazor et al., 2004), the 64-item Attitudes Toward Patient Advocacy scale (Bu & Wu, 2008), and the 48-item NephRN Perceptions Toward Advance Care Planning instrument between February and April 2013.

Concerns About Dying scale. The 10-item Concerns About Dying scale developed by Mazor et al.(2004) measures healthcare provider comfort in caring for dying individuals, spirituality, and patient-related general concerns about death. Items on the Concerns About Dying scale were scored on a 5-point Likert-type scale, from 1 (*disagree completely*) to 5 (*agree completely*) with 3 being *neutral*. The higher the score, the greater was the concern about dying. Mazor et al. (2004) reported a 3-factor solution explaining 66% of model variance with an overall scale Cronbach's alpha of .83. The Concerns About Dying scale was used in this research study to determine construct validity of the Attitude subscale of the NephRN Perceptions Toward Advance Care Planning instrument and to establish internal consistency reliability of this instrument in the nephrology nurse population.

Attitude Toward Patient Advocacy Scale. The 64-item Attitude Toward Patient Advocacy Scale developed by Bu and Wu (2008) measures components of patient advocacy among oncology nurses. The Attitude Toward Patient Advocacy Scale is comprised of two subscales: Attitude Toward Microsocial Advocacy, and Attitude Toward Macrosocial Advocacy. The microsocial advocacy subscale assesses nurse attitudes about advocacy at the patient level and includes acting on behalf of the patient and safeguarding patients' autonomy. The macrosocial advocacy subscale assesses nurse attitudes about policy items and championing social justice. Items are scored on a 6-point Likert-type scale, from 1 (*strongly disagree*) to 6 (*strongly agree*), with negatively worded items reverse coded. Higher scores indicate more positive nurse attitudes toward patient advocacy. Cronbach's alpha for Attitude Toward Microsocial Advocacy subscale was .92, and Cronbach's alpha for the Attitude Toward Macrosocial Advocacy subscale was .95 (Bu & Wu, 2008). These subscales were used in this research study to determine construct validity of the Comfort subscale of the NephRN

Perceptions Toward Advance Care Planning instrument and to establish internal consistency reliability of this instrument in the nephrology nurse population.

Procedure

Participants electronically accessed the survey after they consented to participate in the study, completed Likert-type scale ratings for each of the scale components, and submitted their responses through a link in Survey Monkey®. Upon completion of the survey, participants had the opportunity to enter a sweepstakes for a \$100 Amazon.com gift card.

Data Analysis

The second step in scale development is to evaluate items for their correlations to each other (DeVellis, 1991). Scale items should be intercorrelated, increasing the scale reliability. Item correlation coefficients were examined between and within each proposed subscale to identify item redundancies and lack of fit with other items. Items were analyzed for correlations of .30 to .50 across items within the other subscales. Items were analyzed for correlations between .50 and .70 with other items within its intended subscale (DeVellis, 1991). Items with correlations of .80 or greater suggested redundancy. Items with negative wordings were reverse coded so that positive perceptions received higher scores (DeVellis, 1991). Eleven negatively worded items in the attitude and comfort subscales were re-coded; positive perceptions received higher scores, and negative perceptions received lower scores. Cronbach's alpha was examined for scale and subscale reliability. Missing items were not replaced. Item-total statistics were examined for redundancy and impact on scale if item deleted. Items that were flagged in two or more of the analyses were considered for deletion.

The third step in scale development is to conduct factor analysis (DeVellis, 1991). Factor analysis, unlike scale reliability "can help us determine empirically how many constructs, or latent variables, or factors underlie a set of items" (DeVellis, 1991, p. 92). The Kaiser-Meyer-

Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity were evaluated for adequacy of the factorability of items. Scree plot, eigenvalues, and percent variance were examined to identify the appropriate component structure. Factor loadings explain which variables are associated with which factors. Factor loadings of less than 0.40 were suppressed from interpretation because they explained less than 16% of the variance in the variable (Field, 2009). Finally, Cronbach's alpha for each of the comparison scales was determined to ensure the appropriateness of analysis in the nephrology nurse population. Data were analyzed using SPSS v. 19.0 (IBM, SPSS, 2010).

Results

Each item was compared against the other items in the proposed dimensions of knowledge, attitude, comfort, and support. All four dimensions demonstrated high internal consistencies ($\alpha = .84$ to $.97$).

Item Evaluation

Knowledge. Some items within the knowledge dimension demonstrated very high correlations with each other ($r = .85$ to $.95$) which suggested redundancy. Items 1 through 4 highly correlated with each other and with item 9 ($.88$ to $.95$). Item 3, "I can explain to other nurses what advance care planning is," was more highly correlated with the other items within the dimension (Table 2). Items 1, 2, 4, and 9 were deleted for redundancy. The Knowledge dimension was reduced to 8 items. Cronbach's alpha was $.95$.

Table 2

Initial Knowledge Dimension Inter-Item Correlation Matrix

Inter-item Correlations												
	K1	K2	K3	K4	K5	K6	K7	K8	K9	K10	K11	K12
K1	1											
K2	.95	1										
K3	.93	.97	1									
K4	.88	.91	.93	1								
K5	.76	.74	.79	.81	1							
K6	.75	.76	.80	.77	.82	1						
K7	.65	.62	.62	.66	.58	.61	1					
K8	.86	.89	.86	.87	.78	.75	.67	1				
K9	.92	.94	.97	.91	.82	.76	.63	.86	1			
K10	.76	.75	.79	.83	.84	.84	.64	.78	.80	1		
K11	.85	.89	.86	.82	.75	.72	.64	.87	.83	.745	1	
K12	.66	.68	.68	.64	.62	.49	.54	.66	.66	.54	.72	1

Attitude. Items 1 through 6 in the Attitude dimension were well correlated with each other, and items 7 through 11 in the Attitude dimension with each other. Item 1, “I worry I will upset the patient if I try to discuss advance care planning,” negatively impacted the dimension reliability and had weak correlations with other items in the dimension despite reverse coding (Table 3). Therefore, item 1 was deleted. The Attitude dimension was reduced to 10 items.

Cronbach’s alpha was .86.

Table 3

Initial Attitude Dimension Inter-Item Correlation Matrix

Inter-item Correlations											
	A1	A2	A3	A4	A5	A6	A7	A8	A9	A10	A11
A1	1										
A2	.30	1									
A3	.26	.59	1								
A4	.03	.28	.32	1							
A5	.27	.35	.44	.65	1						
A6	.34	.60	.45	.35	.35	1					
A7	.12	.47	.40	.27	.19	.37	1				
A8	.07	.29	.19	.10	.14	.23	.74	1			
A9	.01	.48	.37	.17	.22	.40	.76	.53	1		
A10	.03	.39	.48	.23	.15	.35	.71	.51	.72	1	
A11	-.06	.18	.18	.13	.16	.16	.59	.44	.50	.67	1

Comfort. There were no issues of redundancy within the inter-item correlation matrix in the Comfort dimension (Table 4). Item 6, “Our patients are not ready to have advance care planning discussions” and Item 8, “I only initiate conversations about advance care planning when the patient begins the conversation” were deleted due to weak correlations with other items in the dimension. The Comfort dimension was reduced to 10 items. Cronbach’s alpha was .91.

Table 4

Initial Comfort Dimension Inter-Item Correlation Matrix

Inter-Item Correlations												
	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12
C1	1											
C2	.77	1										
C3	.86	.82	1									
C4	.69	.60	.68	1								
C5	.54	.50	.46	.31	1							
C6	.33	.27	.27	.24	.40	1						
C7	.70	.60	.57	.57	.56	.35	1					
C8	.25	.32	.28	.19	.06	.34	.12	1				
C9	.35	.42	.54	.36	.14	.37	.25	.39	1			
C10	.62	.54	.55	.41	.30	.39	.61	.34	.64	1		
C11	.48	.46	.44	.06	.52	.18	.45	.36	.32	.59	1	
C12	.71	.71	.65	.52	.69	.31	.69	.24	.15	.53	.59	1

Support. There were no issues of inter-item redundancy in the Support dimension (Table 5). Item 9 related to having private space for advance care planning discussions, item 7 related to supportive peers when conducting advance care planning discussions, and item 13 related to workplace policies for advance care planning; all three items had weak correlations to the other items in the dimension. These three items were deleted. The Support dimension was reduced to 10 items. Cronbach's alpha was .89.

Table 5

Initial Support Dimension Inter-Item Correlation Matrix

Inter-Item Correlations													
	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	S13
S1	1												
S2	.46	1											
S3	.36	.75	1										
S4	.52	.67	.72	1									
S5	.48	.34	.47	.61	1								
S6	.19	.36	.52	.53	.54	1							
S7	.32	.27	.15	.31	.54	.32	1						
S8	.60	.28	.17	.36	.53	.44	.55	1					
S9	.35	.42	.34	.32	.40	.22	.23	.25	1				
S10	.30	.34	.48	.58	.61	.64	.48	.33	.22	1			
S11	.43	.73	.75	.78	.46	.45	.29	.34	.45	.50	1		
S12	.40	.44	.45	.40	.33	-.03	.08	.10	.55	.26	.45	1	
S13	.39	.22	.17	.36	.32	.12	.25	.34	.29	.32	.41	.32	1

Exploratory Factor Analysis

An exploratory factor analysis of the revised scale of 38 items was conducted next.

Principal component analysis using a direct oblimin rotation was selected because the items were expected to correlate (Field, 2009) and because of the limited sample size in relation to items in the scale. The KMO was mediocre at .54 but Bartlett's test of sphericity was significant at .000, indicating adequacy for item factorability (Field, 2009).

There are several methods to determine the number of factors to retain for factor rotation. The most common but least accurate method is to retain all factors with an eigenvalue greater than 1 (Costello & Osborne, 2005). A second method is to examine the scree test, or the graph of the eigenvalues, for the natural bend in the curve (Costello & Osborne, 2005). Multiple factor analyses should then be run at the numbers above and below the component numbers identified from the Scree plot (Costello & Osborne, 2005). Once the factor rotations have been run, a comparison of the item loading tables should identify “the ‘cleanest’ factor structure” that has the best fit to the data and includes “item loadings above .30, no or few item cross loadings, [and] no factors with fewer than three items” (Costello & Osborne, 2005, p. 3).

Eight components had eigenvalues greater than 1. The Scree plot indicated two major points of inflection, at the 4- and 6- component numbers, indicating that 3 to 5 components should be extracted (Field, 2009). Principal component analysis with direct oblimin rotation was run for each of the models, restricting the number of components to be extracted to 6, 5, 4, and 3 respectively.

Pattern matrices were analyzed in item order and again sorted by size. Next, the item loading tables were evaluated for multiple component loadings. The 38-item, 4-component model was selected because it explained nearly 60% of the variance in the model, had the fewest multiple component loadings, had no negative loadings, and had the strongest component loadings. Nine items loaded on Component 1 (Knowledge), ranging from .63 to .87. One item was expected to load on the Support component, “My facility has resources available to me to facilitate advance care planning discussions” loaded on to Component 1 (Knowledge) at .49, so was retained with the knowledge component for further analysis. Nine items loaded on Component 2 (Attitude), ranging from .44 to .84. One item was expected to load on the Comfort component, “I believe patients should be allowed to make autonomous decisions related to

their right to die” loaded strongly on Component 2 (Attitude) at .62, so was retained with the attitude component for further analysis. Eight items loaded on Component 3 (Comfort), ranging from .45 to .80. Comfort 9 did not load on to any of the four factors and was deleted from further analysis. Nine items loaded on Component 4 (Support), ranging from .58 to .72. Support items 2 and 3 loaded stronger on factor 4, but had loadings of .44 and .40 respectively on the knowledge subscale, so were deleted from further analysis.

Six items removed. One item in the Knowledge subscale, Knowledge 7, “I have had formal classes on advance care planning” was removed. Although this item had adequate correlations with the other items in the subscale, it had negative to low correlations between the other subscales, no impact on the subscale reliability if deleted, and this information was asked in the demographic data collection. Two items in the Attitude subscale were removed. Attitude 4, “If I talk about death, the patient may choose it,” and Attitude 5, “If I discuss advance care planning with the patient, the family may blame me for the patient’s choices” did not load on any components in the 4-component model, had low correlations to the other items in the Attitude subscale (Table 3), and had minimal impact on scale reliability if deleted. One item in the Comfort subscale was removed. Comfort 9, “I prefer to care for patients who do not want to discuss ACP” did not load on any components in the 4-component model. This item had adequate correlations to the other items in the Comfort subscale (Table 4) but had low or negative correlations between the other subscales. Two items in the Support subscale were removed. Support 2, “I feel supported by my peers to initiate advance care planning discussions” and Support 3, “I feel supported by physicians to initiate advance care planning discussions” loaded almost equally on components 1 (Knowledge) and 4 (Support); These two items were highly correlated with each other, suggesting similarity of content, and had low or negative correlations between the other subscales.

Principal component analysis for 32 items. Principal component analysis was re-run on the 32-item revised instrument, increasing the KMO sampling adequacy to .67 with Bartlett's test of sphericity remaining significant at .000. The Scree plot had the greatest point of inflection at the 5-component number, supporting the 4-component solution previously identified and explaining 62.42% of variance. Knowledge item 12, "I know when to start the conversation about advance care planning with a patient" loaded most strongly on the Knowledge component (.64), but also loaded strongly on to the Comfort component (.46) so Knowledge item 12 was removed, reducing the NephRN Perceptions instrument to 31 items in four subscales. Principal component analysis using the 31 items revealed that Attitude item 6, "Discussing advance care planning is the same as advocating for euthanasia" did not load on any of the four components, so Attitude item 6 was deleted.

Principal component analysis for 30 items. Principal component analysis was re-run constraining the model to four components. Reducing the final instrument to 30 items resulted in an increase in the KMO measure of sampling adequacy to .70, which is considered 'good' for factor analysis (Field, 2009). The Scree plot had the major inflection at the 5-component number, supporting the 4-component solution previously identified. The final revised NephRN Perceptions Toward Advance Care Planning instrument consists of 30 items measuring the components of Knowledge, Attitude, Comfort, and Support and includes the items listed in Table 6. Support item 12, "My facility has resources available to me to facilitate ACP discussions" loaded on to the Knowledge component. The 4-component solution explained 63.88% of variance. Component 1- Knowledge, explained 31.95% of the model variance. Component 2 - Attitude, explained 15% of the model variance. Component 3 - Comfort, explained 10% of the model variance, and Component 4 - Support, explained 7% of model variance.

Table 6

Principal Component Analysis of the Final 30-item NephRN Perceptions Toward Advance Care Planning Instrument

	Component			
	1	2	3	4
Know where resources are	.89			
Know which resources to use	.88			
Can explain to nurses about ACP	.88			
Know how to talk to pt/family	.88			
Have necessary skills	.86			
Have resources for support	.86			
Facility has resources	.49			
ACP directs comfort care		.89		
ACP allows sense of control		.84		
ACP directs medical care		.81		
ACP decreases family burden		.79		
Pts should define EOL wishes		.64		
Pts should have decisional autonomy		.63		
Pts will lose hope *		.59		
Do not believe in discussing with pt *		.52		
Direct to MD or social worker *			.80	
Am a patient advocate			.72	
Comfortable helping pt identify wishes			.71	
Consider ACP part of role			.64	
Comfortable caring for pts needing ACP			.64	
Best person to initiate discussion			.61	
Comfortable starting discussion			.58	
Only initiate when told to do so *			.48	
Important part of multidisciplinary team				.77
Workload is adjusted				.76
Supported by nurse manager				.76
Manager considers ACP in assignments				.70

Have enough time in work day	.68
MDs believe ACP is part of my role	.66
Work environment is conducive to ACP discussion	.65

Note: * indicates items that were reverse-coded. Items with component loadings less than .40 were suppressed.

Cronbach's Alpha

The revised 30-item instrument and subscales demonstrated strong internal consistencies. The total scale alpha was .92 and the Knowledge, Attitude, Comfort, and Support subscales were .94, .88, .91, and .86 respectively. Cronbach's alpha for the knowledge subscale (.94) would be increased to .96 if the Support 12 item were deleted. This item however, was retained for further testing because knowledge of available resources is an important perception to evaluate. Deletion of any of the items in the Attitude, Comfort, or Support subscales would decrease that subscale reliability. Reliability for the Concerns About Dying scale in this sample of nephrology nurses was moderate at .78. Reliability for the Attitude Toward Patient Advocacy Scale, Attitude Toward Microsocial Advocacy subscale, and Advocacy Toward Macrosocial Advocacy subscale in this sample of nephrology nurses were .94, .92, and .93 respectively.

Discussion and Implications

The results of this pilot study suggest that knowledge, attitudes, comfort, and support are important perceptions to be considered when looking at nephrology nurse participation in advance care planning. This pilot study provides initial evidence that the NephRN Perceptions Toward Advance Care Planning instrument may be a reliable and valid measure for understanding nephrology nurse perceptions toward advance care planning for persons with CKD.

The most significant result of this pilot study is confirmation of the complexity of assessing nurse perceptions of advance care planning. Based on the initial content experts' validity assessment, all items were considered important to exploring the concept of advance care planning. Pilot testing of the data confirmed the multidimensionality of advance care planning. The 4-component solution supported the premise that knowledge, support, attitude, and comfort were important determinants of nephrology nurse perceptions toward advance care planning. As a result of factor analysis, items that were thought to be important or belonging to a particular factor were critically analyzed for their applicability in the scale and deleted if they did not meet the established criteria.

A limitation of the study is the small sample size, necessitating further evaluation in a larger sample. Another limitation of this study is that the sample included primarily Caucasian and female members of a professional nephrology organization, potentially limiting generalizability to nephrology nurses who do not belong to their specialty organization. With the snowball sampling method, it is unknown whether the 20 other nurses were members of their specialty organization or not.

Summary

The NephRN Perceptions Toward Advance Care Planning instrument was developed after a review of the literature that yielded no psychometrically sound measures to assess the complex phenomenon of advance care planning by the nephrology nurse. This instrument shows promise for confirming that the dimensions of knowledge, attitude, comfort, and support are critical factors in explaining nephrology nurse perceptions toward advance care planning. In so doing, perhaps strategies can be developed and implemented to foster greater confidence and comfort with advance care planning among nephrology nurses to enable patients and their families to experience quality of life along with a good quality of death.

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CHAPTER III

VALIDATION OF A MEASURE OF NEPHROLOGY NURSE PERCEPTIONS TOWARD ADVANCE CARE PLANNING

Abstract

Advance care planning is critical for persons with chronic kidney disease because they face a known, shortened lifespan. Nephrology nurses are positioned to participate in advance care planning discussions but do not do this as often as physicians or social workers, nor do they consider advance care planning part of their role. Current research is limited in addressing the reasons why nephrology nurses are less involved, is anecdotal or qualitative in nature, and is focused on limited aspects of advance care planning. There is a paucity of reliable and valid measures exploring nephrology nurse perceptions toward advance care planning. The purpose of this study was to demonstrate the initial reliability and validity evidence of a newly developed measure of nephrology nurse perceptions toward advance care planning. Measuring nephrology nurse perceptions toward advance care planning may facilitate planning of interventions to encourage these nurses to become more active in the process.

Key Words: advance care planning, instrument development, nephrology nurses, factor analysis, measurement

Persons with chronic kidney disease (CKD) have an adjusted mortality rate more than 50% higher than persons without CKD, with the highest rates in persons aged 75 years and older (United States Renal Data System [USRDS], 2013). This increased mortality suggests the need for early and ongoing conversations about end-of-life wishes for persons with CKD. Advance care planning is one component of end-of-life care and is an iterative process of communication between the patient, the family, and the healthcare team about the patient's end-of-life care wishes (Mularski et al., 2007). Many patients want to hear about their prognosis and have these conversations with their healthcare providers (Jeong, Higgins, & McMillan, 2007), and this is true for persons with end-stage renal disease (ESRD; Kataoka-Yahiro, Conde, Wong, Page, & Peller, 2010; Mohlzan et al., 2012). Known patient benefits of advance care planning include supporting the grief process after a patient's death (Kruthaup, 2006), supporting patient autonomy in decision-making (Newton, Clark, & Ahlquist, 2009), opening the lines of communication between the patient and their family members (Sedgewick, Noble, Ho, Kafkia, & van Waeleghem, 2010) and having a positive effect on patients' quality of life and quality of dying (Cohen, Ruthazer & Germain, 2010; Germain, Cohen, & Davison, 2007). Resources are available to help nephrology nurses develop their knowledge and skills about advance care planning (American Nephrology Nurses Association, 2013; Rabetoy & Bair, 2007), which can foster increased comfort with advance care planning. Nephrology nurses, however, do not have these conversations with their patients as often as they should (Rabetoy & Bair, 2007; Yee et al., 2011). To understand why nephrology nurses do not participate as often as they should, it may be helpful to identify nephrology nurse perceptions toward advance care planning for persons with CKD.

Most of the literature on advance care planning in the nephrology population has focused on the role of physicians and social workers but not on the role of nurses. For example,

Arulkumaran, Szawarski, and Philips (2012) discussed complex intangible factors such as culture, religion, and beliefs affecting physician involvement in advance care planning for persons with ESRD but did not consider the role of the nurse in conducting these discussions. Nurses are expected to have an awareness of the needs of their patients and approach each patient to meet their unique cultural, spiritual, and healthcare needs. Davison and Torgunrud (2007) recognized the need for expertise in advance care planning in order to provide comprehensive care to persons with ESRD and developed an interview guide to facilitate advance care planning discussions between physicians and social workers with their patients. This guide could also be appropriate for nurses. Holley and colleagues (1999) identified the importance of including the discussion of withdrawal from dialysis in advance care planning discussions for persons undergoing hemodialysis, but only focused on the physician-patient relationship.

In one nursing study, researchers developed an instrument to assess knowledge, attitudes, and experiences about advance care planning in renal healthcare providers in Singapore (Yee et al., 2011). Findings from this study showed that, compared to other healthcare providers, nurses had less knowledge and skills related to advance care planning, more concerns about the impact the conversations would have on patients, and the lowest perception of advance care planning as part of their role (Yee et al., 2011). No reliability or validity testing was conducted on this instrument (A. Yee, Personal Communication, January 31, 2012). Therefore, the purpose of this study was to develop a measure for nurse researchers to understand nephrology nurses' perceptions toward advance care planning, the NephRN Perceptions Toward Advance Care Planning instrument, and test its initial psychometric properties.

Conceptual Framework

Advance care planning is a complex phenomenon that relies on sufficient structural and process supports to be effective. Berger (2010) contended that advance care planning has two domains: content and process. He defined the content domain as the 'what' and the process domain as the 'why' or 'how.' The content domain relates to "the factual understanding about condition, treatment, likely outcomes, and the choices surrounding these" (Berger, 2010, p. 33) and the process domain relates to how and why decisions are made. Because perceptions influence behavior (Caton & Klemm, 2006; Zomorodi & Lynn, 2010), it is important to understand the 'whys' behind nurses' involvement in advance care planning discussions more so than to outline the 'whats' to accomplish it (Berger, 2010). Although Berger's discussion focused on the patient perspective, this same notion could be applied to expanding research to understand perspectives of the nephrology nurse. For example, Berger stated "admittedly, process issues are far more complex, nuanced, and sometimes more abstract than content issues, and these features likely contribute to their relative neglect in advance care planning and directives" (Berger, 2010, p. 33). By understanding nephrology nurse perceptions toward advance care planning, perhaps the discord between the content of advance care planning and the process of participation in those discussions can be explored.

To guide the development of the NephRN Perceptions Toward Advance Care Planning instrument, a conceptual framework that focused on both structure and process components was needed. The Donabedian (1966) quality of medical care model met these criteria and has been used in various studies related to understanding factors affecting end-of-life care (Bainbridge, Brazil, Krueger, Ploeg, & Taniguchi, 2010; Desharnais, Carter, Hennessy, Kurent, & Carter, 2007; Steinhauser, 2005). Donabedian recognized the difficulty in assessing attitudes and perceptions from a purely outcome focus and recommended evaluating these phenomenon

from a structure and process focus. In the Donabedian model, structure is identified as the internal and external elements necessary to support the dynamic process of care, resulting in an identified outcome. Structure includes the physical place that care is delivered, the administrative support for care, the organizational structure, and the knowledge of the staff providing care (Donabedian, 1966). Process includes the judgments about delivery of care, the coordination of that care, and the interaction with the patient or family in the delivery of care (Donabedian, 1966).

Method

This 3-phase study included the development and testing of the NephRN Perceptions Toward Advance Care Planning instrument. Phase 1 consisted of dimension and item development following the guidelines established by DeVellis (1991), and content validation following the guidelines established by Grant and Davis (1997) with five nurses having expertise in nephrology, end-of-life, or research. Phase 2 consisted of testing the item pool following the guidelines established by DeVellis using an online survey format in a convenience sample of 50 nephrology nurses. Results from Phase 1 and Phase 2 are reported elsewhere (Haras, Astroth, Hesson-McInnis, Kossman, & Woith, 2014). This paper details Phase 3 that consisted of testing the revised 30-item instrument in a larger population of nephrology nurses to confirm the *a priori* factor structure, instrument reliability, and construct validity.

Design and Sample

This survey study was conducted using both an online and paper version of the measures. After obtaining University review board approval, participants for the online version of the survey were recruited from a random sample of 6,000 nephrology nurses from a nephrology nursing organization database and from professional social networking sites.

Participants for the paper version of the survey were recruited at a professional nephrology

nursing conference. Inclusion criteria were U.S. nurses with (a) at least two years of nephrology experience, (b) current work experience with patients with CKD, and (c) prior experience in advance care planning discussions with nephrology patients. Based on an anticipated response rate of approximately 12.5% (Rabetoy & Bair, 2007) from research using this same population, a sample size of 800 nephrology nurses was desired.

Instruments

NephRN Perceptions Toward Advance Care Planning instrument. The purpose of this 30-item newly developed instrument is to measure the structural and procedural components affecting nephrology nurse perceptions toward advance care planning and was based on Donabedian's (1966) quality model of structure, process, and outcomes.

From a prior review of the literature, four major dimensions were identified that affect nurse involvement in the advance care planning process; knowledge (Colville & Kennedy, 2012; Germain et al., 2007; Yee et al., 2011; Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010), support (Ceccarelli, Castner, & Haras, 2008; Colville & Kennedy, 2012; Kerfoot, 2012), attitude (Ali & Ayoub, 2010; Yee et al., 2011; Zhou et al., 2010), and comfort (Ceccarelli et al., 2008; Jeong et al., 2010; Yee et al., 2011; Zhou et al., 2010). In this study, structure refers to the knowledge of and support for advance care planning. Items in the knowledge dimension assessed nurses' perceptions about their ability to conduct advance care planning discussions and their knowledge about resource availability. Items in the support dimension assessed nurses' perceptions about the level of workload adjustment and environmental space to conduct advance care planning discussions. Process refers to the nurse attitudes and comfort with advance care planning. Items in the attitude dimension assessed nurses' perceptions of the positive and negative aspects of advance care planning. Items in the comfort dimension

assessed nurses' perceptions of their role in advance care planning discussions and in patient advocacy.

Participants scored items on a 4-point Likert-type scale from 1 (*strongly disagree*) to 4 (*strongly agree*). Higher scores in each dimension indicated agreement with the items reflective of positive nephrology nurse perceptions toward advance care planning. Phase 2 exploratory factor analysis using principal component analysis with direct oblimin rotation revealed a 4-component solution that best grouped the items and explained nearly 64% of the model variance. Phase 2 factor and item analyses reduced the instrument to 30 items with a Cronbach's alpha of .92. Cronbach's alphas for the Knowledge, Attitude, Comfort, and Support subscales were .94, .88, .91, and .86, respectively (Haras et al., 2014). Cluster analysis did not differ significantly from the results of exploratory factor analysis. The sample size was adequate for factor analysis (KMO = .70, Bartlett's test of sphericity = .00; Haras et al., 2014).

Concerns About Dying scale. The 10-item Concerns About Dying scale developed by Mazor, Schwartz, and Rogers (2004) measures three subscales of healthcare provider comfort in caring for dying individuals, spirituality, and patient-related general concerns about death. Factor analysis revealed a 3-factor solution explaining 66% of the variance. Cronbach's alpha for the overall scale in Phase 2 of this study was .78 (Haras et al., 2014). Although three factors were identified in this scale, the total scale score was used as part of construct validity testing for the Attitude and Comfort subscales of the NephRN Perceptions Toward Advance Care Planning instrument and the instrument as a whole. Items were scored on a 5-point Likert-type scale, from 1 (*disagree completely*) to 5 (*agree completely*) with 3 being *neutral*. Higher scores on the Concerns About Dying Scale indicate greater anxiety about death and dying so were expected to have weak and negative correlations to the Attitude subscale of the NephRN Perceptions Toward Advance Care Planning instrument. Increased anxiety about death and

dying negatively affect comfort with end-of-life discussions (Peck, 2009) so a moderate, negative correlation with the Comfort subscale was expected. The Concerns About Dying scale was expected to have moderate, negative correlations with the entire NephRN Perceptions Toward Advance Care Planning instrument, supporting both convergent and discriminant validity at the same time.

Attitude Toward Patient Advocacy Scale. The 64-item Attitude Toward Patient Advocacy Scale developed by Bu and Wu (2008) measures components of patient advocacy among oncology nurses. This instrument has two subscales: the Attitude Toward Microsocial Advocacy subscale that measures nurse attitudes about advocacy at the patient level, and the Attitude Toward Macrosocial Advocacy subscale that measures nurse attitudes about patient advocacy at the broader policy and social justice level. Items were scored on a 6-point Likert-type scale, from 1 (*strongly disagree*) to 6 (*strongly agree*), with negatively worded items reverse coded. Higher scores on the scale indicated more positive attitudes and support toward patient advocacy. Factor analysis revealed a 2-factor solution explaining 33% of the variance. Cronbach's alpha for the overall scale in Phase 2 of this study was .94; Cronbach's alpha for the Attitude Toward Microsocial Advocacy subscale was .92; Cronbach's alpha for the Attitude Toward Macrosocial Advocacy subscale was .93 (Haras et al., 2014). The Attitude Toward Microsocial Advocacy subscale was used as part of construct validity testing for the Comfort subscale of the NephRN Perceptions Toward Advance Care Planning instrument. Positive attitudes toward patient advocacy are expected to be congruent with positive perceptions toward comfort in conducting advance care planning discussions. Higher scores on this subscale were expected to correlate with higher scores on the Comfort subscale of the NephRN Perceptions Toward Advance Care Planning instrument. The Attitude Toward Macrosocial Advocacy subscale was used as part of construct validity testing for the Comfort subscale of the

NephRN Perceptions Toward Advance Care Planning instrument. Because the NephRN Perceptions Toward Advance Care Planning instrument is not intended to measure advocacy from the broader social perspective, correlations to the macrosocial subscale were expected to be weak.

Procedure

A postcard with a brief description of the research project, researcher's contact information, and link to the electronic survey was sent via U.S. mail to the 6,000 nephrology nurses randomly selected from the nephrology nurse organization database. Forty-one postcards (0.7%) were returned as undeliverable. Addresses were updated from returned postcards, and where no forwarding address was found, those addresses were deleted from the mailing list. A reminder postcard with an easier-to-access web address was sent to 5,976 of the original 6,000 participants. In addition, a request for nephrology nurse participation was placed in professional networking sites. The link to the survey was included in the request, along with a statement that if the person had previously completed any version of the survey, to please disregard this request.

Participants accessed the electronic survey in SurveyMonkey®. After the informed consent was reviewed and accepted, participants received the three instruments in random order to reduce order of completion bias and impact of participant fatigue. Upon completion of the electronic version of the survey, participants were invited to enter a sweepstakes to win a \$100 Amazon.com gift card. Participants completing the paper copy survey returned them to the researcher via U.S. mail. There was one version of the paper survey, with the three instruments presented in the following order: NephRN Perceptions Toward Advance Care Planning, Concerns about Dying, and Attitude Toward Patient Advocacy. Participants completing the paper survey did not have the opportunity to participate in the sweepstakes drawing due to

limitations within the sweepstakes manager. Two hundred-thirty surveys were completed: 222 electronic and 8 paper.

Data Analysis

Data were cleaned; cases with more than 10 (33.33%) missing questions from the NephRN Perceptions Toward Advance Care Planning instrument were deleted from further analysis. The final sample included 216 surveys. A full-information maximum likelihood imputation procedure was used to estimate the 6.34% missing values from the usable surveys. Confirmatory factor analysis validated the number of underlying factors associated with the latent, or unobservable, variable of nephrology nurse perceptions toward advance care planning (DeVellis, 1991) and examined the relationship among the dimensions in the instrument. The NephRN Perceptions Toward Advance Care Planning instrument underwent correlation analyses to determine whether this new instrument was similar yet distinctly different from existing measures of related concepts and to explore the relationship between each dimension. Descriptive statistics were calculated for each dimension and each instrument. Cronbach's alphas were calculated for each instrument to determine internal consistency reliability in the nephrology nurse population. Secondary data analysis explored nephrology nurse perceptions toward advance care planning.

Results

There were 216 usable surveys from nephrology nurses ranging in age from 28 to 74 years ($M = 52.75$, $SD = 9.25$). The nurses had 3 to 47 years ($M = 28.09$, $SD = 10.58$) experience in nursing and 3 to 48 years ($M = 21.72$, $SD = 10.36$) in nephrology. Most nurses were female (93%), Caucasian (82%), and practiced in an outpatient setting (65%). Half of the nurses had a formal course in death and dying since becoming a nurse; some (8%) were not sure if they had taken a course. Less than half (41.5%) of the nurses reported five or more advance care planning

discussions per year, and 33% reported 10 or more conversations per year. The number of times that advance care planning discussions held in one year were then categorized to determine if there was any significant difference in responses by participants based on frequency of discussions. Frequency of discussions was categorized from 0 to 4, 5 to 10, 11 to 15, and greater than 16 per year. Most nurses ($n = 96$) reported 16 or more discussions per year, followed by 0 to 4 ($n = 69$), and 5 to 10 ($n = 42$). Nine nurses reported 11 to 15 discussions per year. Most of the nurses had personal experience with advance care planning for himself or herself or a family member (73%), and were overwhelmingly satisfied with that experience (68%). The range of time to complete the survey was 7 to 60 minutes ($M = 25, SD = 10.72$).

Confirmatory Factor Analysis

For each model tested, the following steps were conducted to determine the relative fit of the model. First, theta-deltas were reviewed for Heywood cases indicating that the variable must be modified (Kenny, 2011). Second, squared multiple correlations for each variable were examined, indicating the variance of each item accounted for by each factor. Low correlations meant that the item was not contributing significantly to the overall factor structure, and was considered for deletion. Third, the completely standardized solution for lambda-x was examined. Each variable score was reported for its respective factor and interpreted similar to the correlations in exploratory factor analysis. Items with low correlations to each other indicate a poor fit with the factor structure and these items were considered for deletion. Finally, goodness of fit statistics were examined to determine the overall soundness of the model. For a good-fitting model, Chi-square should be low and non-significant (Kenny, 2012). The ratio of Chi-square to degrees of freedom (df) should be low, indicating a better fitting model. A ratio of 2:1 or less was sought. The root mean square error of approximation (RMSEA) was examined for a value of 0.08 or less, indicating a good fitting model (Kenny, 2012). The non-normed fit index

(NNFI) or Tucker-Lewis Index, was examined along with the comparative fit index (CFI) for values greater than .90, and the standardized RMR (SRMR) for a value of .08 or less, all indicating a good fitting model (Kenny, 2012).

Table 7 indicates the goodness of fit statistics for the alternative models and the final model selected. Models 1 through 6 were poor fitting. Model 7 with 13 items was approaching a good-fitting model, but the Tucker-Lewis Index (NNFI) was below acceptable limits. When the instrument was reduced to 12 items with three items in each subscale, model 8 indicated a good fit across all parameters. Model 9 as a one-factor, 12-item assumption, did not meet any of the parameters for a good-fitting model. This supports the *a priori* assumption that there are four unique but related dimensions to nephrology nurse perceptions toward advance care planning.

Table 7

Goodness of fit Indices for Alternative Models (n = 216)

Model Criteria for a good fit:	χ^2 Small	χ^2/df <2	RMSEA <.05	NNFI >.90	CFI >.90	S-RMR <.08
1 – 30 items (4 factors)	700.67	1.76	0.24	0.35	0.41	0.30
2 – 26 items (4 factors)	547.65	1.87	0.24	0.39	0.45	0.24
3 – 22 items (4 factors)	446.37	2.20	0.25	0.39	0.47	0.26
4 – 18 items (4 factors)	281.39	2.18	0.20	0.52	0.60	0.22
5 – 16 items (4 factors)	181.90	1.86	0.13	0.67	0.73	0.11
6 – 14 items (4 factors)	137.91	1.94	0.12	0.72	0.78	0.09
7 – 13 items (4 factors)	94.65	1.60	0.09	0.82	0.87	0.07
8 – 12 items (4 factors)	67.69	1.41	0.08	0.89	0.92	0.07
9 – 1 factor (12 items)	217.96	4.04	0.44	0.19	0.34	0.30
10 – Hierarchical (4 factors)	68.58	1.37	0.08	0.90	0.93	0.07

Table 8 indicates the maximum likelihood completely standardized parameter solutions for each item in each subscale and the squared multiple correlations indicating overall contribution to the factor on which the item loaded and the variance in the item explained by the factor.

Table 8

Completely Standardized Parameter Solutions for Model 8

	Knowledge <i>Lambda-X</i>	Attitude <i>Lambda-X</i>	Comfort <i>Lambda-X</i>	Support <i>Lambda-X</i>	<i>Squared Multiple Correlations</i>
Know1	0.81				0.65
Know3	0.77				0.59
Know4	0.93				0.87
Attitude3		0.73			0.53
Attitude6		0.87			0.75
Attitude7		0.71			0.50
Comfort2			0.91		0.83
Comfort3			0.85		0.73
Comfort5			0.87		0.76
Support2				0.81	0.65
Support5				0.74	0.55
Support7				0.79	0.63

Table 9 illustrates the strength of the item-to-factor loadings and the correlation of each factor to the overall NephRN Perceptions Toward Advance Care Planning instrument.

Table 9

Hierarchical Confirmatory Factor Analysis Standardized Solutions for 4-factor Model

	Knowledge <i>Lambda-Y</i>	Attitude <i>Lambda-Y</i>	Comfort <i>Lambda-Y</i>	Support <i>Lambda-Y</i>
Know1	0.78			
Know3	0.76			
Know4	0.88			
Attitude3		0.66		
Attitude6		0.84		
Attitude7		0.66		
Comfort2			0.90	
Comfort2			0.81	
Comfort5			0.86	
Support2				0.76
Support5				0.72
Support7				0.78
Gamma	0.82	0.39	0.93	0.66

Second-order Hierarchical Confirmatory Factor Analysis

Second-order hierarchical confirmatory analysis (Model 10) validated the appropriateness of the 4-factor structure and explored the relationship of each variable to the latent variable of nephrology nurse perceptions toward advance care planning. Perception of comfort had the highest correlation with nephrology nurse perceptions toward advance care planning, gamma (r) = .93, followed by knowledge (r = .82), support (r = .66), then attitude (r =

.39). Figure 2 illustrates the factor correlations, item correlations, and item contributions to the NephRN Perceptions Toward Advance Care Planning instrument. There was a significant difference ($p = .03$) in perception of comfort scores for nurses who reported 0 to 4, 5 to 10, 11 to 15, or 16 or more advance care planning discussions per year, with the highest comfort scores in the 11 to 15 discussions per year group ($M = 3.44, SD = .41$). Interestingly, the nurses who reported 16 or more discussions per year had the lowest perception of comfort ($M = 3.01, SD = .74$).

There was a significant difference ($p = .01$) in perception of knowledge between nurses who reported 0 to 4, 5 to 10, 11 to 15, and 16 or more discussions per year. Nurses who reported between 11 and 15 discussions per year had the highest perception of knowledge ($M = 3.59, SD = .36$) and nurses reporting 16 or more discussions per year had the lowest perception of knowledge ($M = 2.98, SD = .64$). It is unclear why this discrepancy in perception exists, which warrants further investigation in a future study. The availability of advance care planning resources specific to nephrology nurses may explain the positive perception of knowledge about advance care planning in this population, indicating that these resources are effective.

Figure 2. Empirical Results from a Second-Order Hierarchical Model

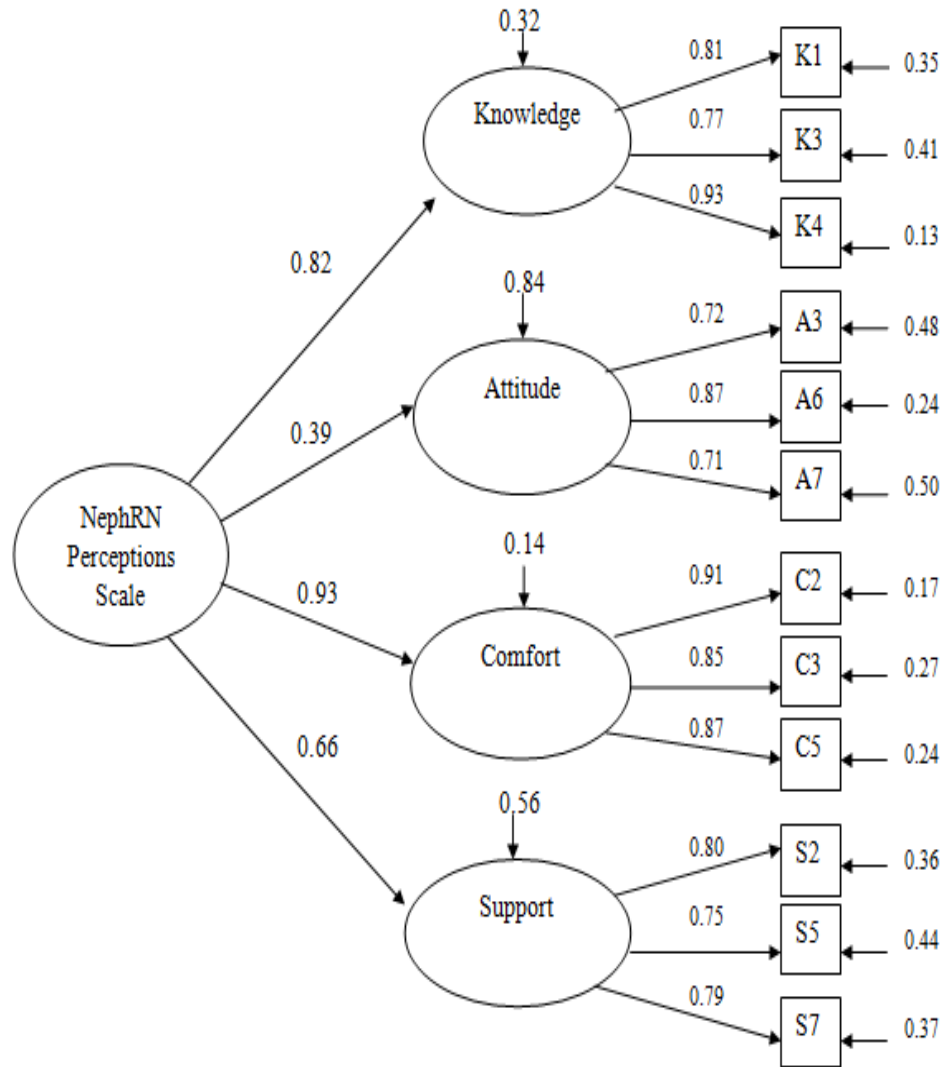


Figure 2. Hierarchical confirmatory factor analysis model of multidimensionality of nephrology nurse perceptions toward advance care planning. Completely standardized solution estimates. The residual variance components (error variances) indicate that amount of unexplained variance.

Scale Reliability

The reduced 12-item NephRN Perceptions Toward Advance Care Planning instrument underwent internal consistency reliability analysis. Tables 10 and 11 illustrate the correlations between each subscale dimension and the internal consistency of the final 12-item NephRN

Perceptions Toward Advance Care Planning instrument. The subscale correlations were significant and weakly to moderately correlated with each other, supporting the multidimensionality of this instrument. Cronbach's alpha for this instrument was high (.86) and subscale reliabilities were moderate to high (.76 to .90).

Table 10

Correlations between Each Dimension of the NephRN Perceptions Toward Advance Care Planning Instrument

	Knowledge	Attitude	Comfort	Support
Knowledge	1			
Attitude	.27**	1		
Comfort	.66**	.34**	1	
Support	.42**	.18*	.49**	1

Note: * = significant at $p = .011$, ** = significant at $p = .000$

Table 11

Reliability Statistics for the 12-item NephRN Perceptions Toward Advance Care Planning Instrument

Subscale/Item	Cronbach's Alpha
Knowledge	.86
<ul style="list-style-type: none"> I can explain what ACP is I know which resources to direct others to I know how to talk to patients/families about ACP 	
Attitude	.81
<ul style="list-style-type: none"> ACP helps direct medical care of the patient ACP allows patients to have a sense of control Patients should have the right to define their end-of-life care wishes 	
Comfort	.90
<ul style="list-style-type: none"> I see myself as patient advocate by initiating ACP discussions I am comfortable helping patients identify their end-of-life care wishes I am comfortable starting the conversation about ACP with a patient 	
Support	.76
<ul style="list-style-type: none"> I have enough time in the day to conduct ACP discussions My nurse manager considers ACP discussions in workload assignments I feel my work environment is conducive to have ACP discussions 	
NephRN Perceptions Toward Advance Care Planning instrument	.86

Internal consistency reliability for The Attitude Toward Patient Advocacy Scale and the Concerns About Dying scale was tested in the nephrology nurse population to ensure adequacy of those scales for comparison with the NephRN Perceptions Toward Advance Care Planning instrument. Cronbach's alpha for the Concerns About Dying scale was moderate (.76). Cronbach's alpha for the Attitude Toward Patient Advocacy scale was high (.96), with high subscale reliabilities of .94 and .95 respectively for the microsocial and macrosocial subscales.

Construct Validity

The NephRN Perceptions Toward Advance Care Planning instrument as a whole demonstrated significant correlations between the Concerns About Dying scale and the two subscales of the Attitude Toward Patient Advocacy scale, $p = .000$. Even though there are no 'hard and fast rules' to determine convergent and discriminant validity, convergent correlations should always be higher than discriminant correlations (Trochim, 2006). Bollen (1989) reports that correlations should be statistically significant and large. Table 12 displays the correlations between the subscales and overall NephRN Perceptions Toward Advance Care Planning instrument, the Attitude Toward Microsocial Advocacy subscale, and the Attitude Toward Macrosocial Advocacy subscale of the Attitude Toward Patient Advocacy scale (Bu & Wu, 2008), and the Concerns About Dying scale (Mazor et al., 2004). Correlations ranged between $-.34$ and $.42$, demonstrating both convergent and discriminant validity and supporting the uniqueness of the NephRN Perceptions Toward Advance Care Planning instrument from existing measures of end-of-life care.

Table 12

Construct Validity of the NephRN Perceptions Toward Advance Care Planning Instrument

	CAD	AMIA	AMAA
Knowledge	-.30**	.28**	.25**
Attitude	-.18*	.30**	.08
Comfort	-.31**	.38**	.26**
Support	-.18*	.29**	.20*
NephRN	-.34**	.42**	.28**

Note: CAD = Concerns About Dying scale (Mazor et al., 2004); AMIA = Attitude Toward Microsocial Advocacy subscale; AMAA = Attitude Toward Macrosocial Advocacy subscale of the Attitude Toward Patient Advocacy Scale (Bu & Wu, 2008).

* $p < .01$; ** $p = .000$

Face Validity

Face validity was assessed by asking participants if they had anything to share about the survey to determine the meaningfulness of the survey to the participants responding. The question was intentionally vague so as not to bias the participant responses to a pre-determined answer about the importance of the survey. Approximately 23% of participants responded to the question. Participant responses are reflective of the four dimensions and highlight the importance of this topic. Examples of the narrative responses include:

- “This is such an important aspect of care & should be initiated as soon as possible so the person will not think that he/she is about to die. Thank you for assessing the current state of affairs!”
- “I felt that having the close relationship that we in ESRD have with our outpatients allowed me to explore these options, seek referrals, education, and provide support to the patients

and families. I have family members who still call with questions and concerns although their loved one has gone. I believe this is a benefit of working in chronic care.”

- “Topic is very important and not addressed sufficiently in the CKD community. Dialysis is inherently a life sustaining treatment and many physicians have difficulty supporting the patient in making decisions to end treatment or opt to not begin. Quality of life is intensely personal and must be explored with each patient in order to help them make an informed decision.”
- “I feel pretty passionate about Advance Care Planning for the ESRD population as they all have the potential for a sudden event. Though I have been instructed to incorporate these counseling sessions in my work, no time has been allotted to carry it out. I need to shuffle my other responsibilities to accomplish this "task.”

Secondary Findings

Overall, nurses had a positive perception toward advance care planning ($M = 3.13, SD = .48$) on a 1 to 4 scale. Participants had the highest score in the attitude dimension about advance care planning ($M = 3.67, SD = .45$). Participants scored the next highest in the comfort dimension ($M = 3.14, SD = .67$). Perception of knowledge was similar to perception of comfort ($M = 3.11, SD = .64$). Participants scored the lowest in their perception of support for advance care planning ($M = 2.46, SD = .66$). Participants generally had low concerns about dying ($M = 2.17, SD = .61$) and positive attitudes toward patient advocacy, with a more positive attitude toward microsocial advocacy ($M = 5.54, SD = .42$) than with attitude toward macrosocial advocacy ($M = 5.05, SD = .72$).

There was a significant difference between groups for perception of knowledge, $F(3,212) = 3.96, p = .01$ and for perception of comfort, $F(3,212) = 3.01, p = .03$ based on frequency of advance care planning discussions. There were no significant differences between

groups for perception of attitude, $F(3, 212) = 1.37, p = .25$, or for perception of support, $F(3, 212) = .40, p = .75$. The participants who responded that they had between 11 and 15 discussions per year had the highest perceptions in knowledge ($M = 3.59, SD = .36$), attitude ($M = 3.93, SD = .22$), and comfort ($M = 3.44, SD = .41$). These nurses had the second lowest perception of support for advance care planning ($M = 2.48, SD = .47$).

Discussion

Phase 3 was designed to test the factor structure of the NephRN Perceptions Toward Advance Care Planning instrument in a target population of 800 nephrology nurses. The initial response was vigorous, with over 100 respondents in the first week the survey was open. The final 130 surveys were returned over the next six weeks and included eight paper copies. The overall response rate of 3.8% was well below the expected and desired rate of 12.5% obtained by Rabetoy and Bair (2007), the rate of 39.5% obtained by Thomas-Hawkins, Denno, Currier, and Wick (2003), or the rate of 52% obtained by Thomas-Hawkins, Flynn, and Clarke (2008) from a similar database. One possible explanation for the low response rate is perhaps nephrology nurses were generally uncomfortable with advance care planning or their role in the advance care planning process.

Confirmatory factor analysis supported the *a priori* hypothesis from Phase 1 and 2 that there were four distinct but related dimensions influencing nephrology nurse perceptions toward advance care planning. Consistent with the findings of others, knowledge, attitudes, and experiences were known to impact nurse participation in advance care planning (Ceccarelli et al., 2008; Colville & Kennedy, 2012; Yee et al., 2011). Perceived support for advance care planning influenced positive perceptions by nurses (Kerfoot, 2012; Yee et al., 2011).

Perception of comfort was the strongest dimension associated with nephrology nurse perceptions toward advance care planning. In a comparison of mean scores, these nephrology

nurses scored the second highest in their perception of comfort with advance care planning. The nurses agreed that they saw themselves as patient advocates, felt comfortable identifying patients' end-of-life care wishes, and felt comfortable starting the conversation about advance care planning with patients. The nurses in this study had an average of 22 years of nephrology experience and the majority had personal, positive experiences with advance care planning, consistent with the findings of Lipson, Hausman, Higgins and Burant (2004). According to Lipson and colleagues (2004), "increased confidence in advance directive discussion skills...was found to be a significant predictor of actual advance directive discussions" (p. 792).

Perception of knowledge was the second strongest dimension associated with nephrology nurse perceptions toward advance care planning. In a comparison of mean scores, these nephrology nurses scored the third highest in their perception of their overall knowledge about advance care planning and their preparation for the discussions. These nurses agreed that they can explain what advance care planning is, they know which resources to direct patients or family members to for more information about advance care planning, and know how to talk to patients or family members about advance care planning. Prior research has shown that increased knowledge of a subject is correlated with increased comfort in that experience. Seal (2007) found nurses on specialty units in the acute care setting had a significant increase in post-test scores following an educational intervention about advance directives. Less than half of the nurses in this study reported participating in a formal death and dying course and half of the nurses reported more than five advance care planning discussions per year.

Perception of support was the third strongest dimension association with nephrology nurse perceptions, confirming the need for a strong structural base to enable nurses to participate in this important process. Items in the Support dimension reflected managerial support for the importance of advance care planning discussions by providing time and space

for the nurse to engage in these discussions. In a comparison of mean scores, these nephrology nurses scored the lowest in their perception of support for advance care planning. These nurses generally disagreed that they had enough time in their day to conduct advance care planning discussions with patients or family, that their nurse manager considers advance care planning discussions in workload assignments, and that the workload is conducive to have advance care planning discussions with patients and families. These findings are consistent with those by Seal (2007) who found that patient advocacy by nurses on specialty units in the acute care setting increased in relation to the amount of administrative support for advance care planning, and by Thomas-Hawkins et al., (2003) and Gardner & Walton (2011) who found that workplace barriers impacted nurses' ability to provide quality patient care.

Perception of attitude was the weakest dimension associated with nephrology nurse perceptions toward advance care planning, indicating that nurses were the least influenced by their personal attitudes when interacting with patients about advance care planning. In a comparison of mean scores, these nephrology nurses scored the highest in their overall attitude about advance care planning. These nurses most strongly agreed that advance care planning helps direct medical care of the patient when he or she is seriously ill, advance care planning allows patients to have a sense of control over their lives, and that patients should have the right to define their end of life care wishes. These nurses reported overwhelmingly positive experiences with advance care planning either for themselves or for their families. These findings are consistent with those found by Zomorodi and Lynn (2010) who found nurses' prior experiences with end-of-life interventions shape nurses' attitudes and the way they interact with patients needing end-of-life interventions.

Internal consistency reliability was confirmed in the final 12-item NephRN Perceptions Toward Advance Care Planning instrument. Scale and subscale reliabilities were moderate to

high, supporting the relationship of each item to the others within the subscale and to the instrument as a whole. This implies the reduced-item instrument is reliable and valid in quickly assessing nephrology nurse perceptions toward advance care planning. This assessment could be used in clinical settings to inform administrators of the structure and process factors that may require interventions to increase nurse participation in advance care planning discussions.

Advocacy at the microsocial patient level was moderately positively correlated with the NephRN Perceptions Toward Advance Care Planning instrument as a whole. Bu and Wu (2008) found that patient advocacy can positively influence patient outcomes by “(a) safeguarding patients’ autonomy, (b) acting on behalf of patients, and (c) championing social justice” (p. 65). This illustrates that nurses should have a sense of patient advocacy to engage in advance care planning discussions.

Concerns about dying were negatively correlated with the NephRN Perceptions Toward Advance Care Planning instrument as a whole, supporting the notion that the greater the concerns about death and dying, the less likely the nurse would have positive perceptions toward advance care planning. This finding was consistent with that of Peck (2009) who found that increased anxiety about death and dying resulted in decreased participation in end-of-life discussions.

Participant comments at the end of the survey indicated the participants were passionate about advance care planning and involvement of the patient or family in end-of-life discussions. Some respondents were appreciative of the focus on advance care planning, supportive of its importance, and expressed interest in reading the results of the study. Three participants commented the survey was too long. The length of the survey was necessary to evaluate the uniqueness of the NephRN Perceptions Toward Advance Care Planning instrument as distinct from existing measures of related end-of-life concepts. It also was necessary to

determine internal consistency reliability of the Concerns About Dying scale and the Attitude Toward Patient Advocacy scale and subscales within the nephrology nurse population in order to evaluate correlations with the NephRN Perceptions Toward Advance Care Planning instrument. Both instruments have established internal consistency reliability in the general healthcare and oncology nurse populations respectively, and this study confirmed internal consistency reliability in the nephrology nurse population. To reduce participant fatigue in the future if this study were to be replicated, only one instrument would be used to determine convergent and discriminant validity.

Limitations

There are some limitations to this study. Threats to internal validity include technical problems and the effect of testing. Threats to external validity include convenience sampling, gender bias, and racial bias, and participants knowing they are part of a study, which would affect recall of prior advance care planning discussions. First, participants indicated survey access problems. A shortened URL was created to facilitate manual entry and included in the reminder postcard. Despite the shortened URL, at least 20 participants emailed the researcher indicating access problems. The link was included in the response email to the potential participant, who was then able to access the survey. Perhaps there were firewalls blocking access. It is unknown how many other potential participants experienced difficulty accessing the survey and therefore gave up trying. The low response rate is perhaps because the participants had to enter the web address into their browser rather than clicking on an embedded link in an electronic e-mail. Although a respond by date was included, participants perhaps put the postcard aside and forgot to proceed with the survey. Second, the small sample size relative to the number of nephrology nurses limits generalizability to a wider nephrology nurse population. The sample included primarily female and Caucasian nephrology nurses who were members of

their specialty organization, limiting generalizability to nephrology nurses who are not members of the specialty organization. Due to the small sample size, confirmatory factor analysis with the initial 30 items did not meet the minimum 5:1 sample to parameter ratio (Field, 2009). When the scale was reduced to 12 items with 30 parameters however, the ratio was 7.2:1, well within acceptable parameters. Third, the self-selecting and self-reporting nature of the study asked nurses to recall their perceptions from prior advance care planning experiences and they may have been more positively remembered than what they actually were at the time. Nurses may have responded more favorably to the questions knowing they were part of a research study.

Summary

In this instrument development study, comfort in conducting and participating in advance care planning discussions was the most critical dimension determining nephrology nurse perceptions toward advance care planning. Knowledge of and administrative support for advance care planning were important dimensions that contributed to nurses' overall perception toward advance care planning. Attitude toward advance care planning was important but had a lesser role in determining nephrology nurse involvement in advance care planning discussions with persons with CKD. Educational resources to increase knowledge are plentiful; combined with a supportive environment, nephrology nurses will have the necessary structural components in place to improve the process of advocating and participating in advance care planning discussions with persons with CKD. This study confirmed that it is possible to develop a valid and reliable tool to measure advance care planning perceptions of nephrology nurses.

Implications

For Research

Future research could focus on retesting this instrument in a larger nephrology nurse population and including more nephrology nurses who are not members of their specialty organization. Testing this instrument in a variety of nursing specialties could confirm the dimensionality of advance care planning and determine this instrument to be reliable and valid in a variety of populations. Another possible direction to explore is that there may be more than four factors involved in nephrology nurse perceptions toward advance care planning. The 4-component model could not explain 36% of the model variance, suggesting that there may be additional factors not yet discovered by current research.

For Practice

Results of this study could inform nurse administrators of the need to implement strategies to support nephrology nurses in advance care planning in order to increase their comfort with the process of advance care planning. Nurse administrators could utilize this instrument in their own quality improvement initiatives within their respective patient-care areas to benchmark current performance and identify areas for improvement.

For Education

Nurse educators can use this information to structure formal educational experiences for nursing students and nurses to increase their exposure to advance care planning and end-of-life patient experiences. Clinical experiences that include participation in advance care planning discussions and end-of-life care may increase nursing student and nurse comfort in participation in these activities.

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