pISSN 1229-1285 • eISSN 2287-6189

## Comparison of Spiritual Needs between Patients with Progressive Terminal Kidney Disease and Their Family Caregivers

## Ye-Jean Kim, R.N., Ph.D., Oknan Choi, M.S., R.N.\*, Biro Kim, M.D.\*, Jiyoung Chun, R.N., Ph.D.<sup>+</sup> and Kyung-Ah Kang, R.N., Ph.D.<sup>+</sup>

Department of Nursing, Sahmyook Health University, \*Division of Nephrology, Department of Internal Medicine, Sahmyook Medical Center, <sup>†</sup>College of Nursing, Sahmyook University, Seoul, Korea

Purpose: The purpose of this study was to compare differences in spiritual needs (SNs) and factors influencing SNs between patients with progressive terminal kidney disease and their family caregivers. Methods: An explorative comparative survey was used to identify the SNs of patients (N=102) with progressive terminal kidney disease undergoing hemodialysis and their family caregivers (N=88) at a general hospital located in Seoul, South Korea. The data were analyzed using descriptive statistics, the chi-square test, the independent t-test, one way analysis of variance, the Scheffé test, and multiple regression with dummy variables. Results: The SNs among family caregivers were higher than in the patient group. SNs were higher among those who were religious in both groups. Loving others was the highest-ranked subdimension in the patient group, followed in descending order by maintaining positive perspective, finding meaning, Reevaluating beliefs and life, asking "why?", receiving love and spiritual support, preparing for death, and relating to God. In the family group, the corresponding order was maintaining positive perspective, loving others, finding meaning, receiving love and spiritual support, preparing for death, relating to God, and asking "why?". The factors that had a negative influence on the level of SNs were not being religious in the patient group and having only a middle school level of education in the family group. Conclusion: The results of this study may serve as evidence that spiritual care for non-cancer patients' family caregivers should be considered as an important part of hospice and palliative care.

Key Words: Palliative care, Chronic renal insufficiency, Patients, Family, Spirituality, Needs assessment

Received December 28, 2019 Revised February 1, 2020 Accepted February 3, 2020

#### Correspondence to Jiyoung Chun

College of Nursing, Sahmyook University, 815 Hwarang-ro, Nowon-gu, Seoul 01795, Korea Tel: +82-2-3399-1593 Fax: +82-2-3399-1594 E-mail: jychun0827@gmail.com

### INTRODUCTION

#### 1. Background

Since the Hospice, Palliative Care, and Life-Sustaining Treatment Decision-Making Act entered into force in April 2018, eligibility for hospice and palliative care has been expanded to cover non-cancer patients with HIV/AIDS, chronic obstructive pulmonary disease, and liver cirrhosis (1). Terminal illness is defined as a chronically aggravating illness for which recovery is difficult to expect even with appropriate treatment, although clinical specialists recognize the complexity of defining terminally ill patients with non-cancer diseases (2).

According to the 2014 Korea National Health and Nutrition Examination Survey, health behavior patterns among Korean adults are highly related to the prevalence of obesity, diabetes,

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (http://creativecommons.org/licenses/by-nc/4,0/) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

and hypercholesterolemia (3,4), of which diabetes and hypertension are known to be the first and second most common causes of chronic kidney disease (CKD) in Korea as of 2015 (5). CKD is increasingly common in Korea, reflecting the growing number of patients with chronic diseases such as diabetes and hypertension. Patients with progressive terminal kidney disease not only find it hard to expect a full recovery, but may also suffer from serious disabilities that interfere with carrying out daily activities such as sleeping, eating, and urinating, as well as motor neurological and mental/cognitive disabilities (6). The progressive nature of CKD eventually leads to death from the disease itself and/or accompanying complications (7). The annual mortality of patients receiving dialysis for CKD has been reported to be 20%, and the 3-year survival rate among patients aged 65 and older who do not manage their disease well was found to be 60% or less (8).

In light of these circumstances, CKD patients and their family caregivers require holistic care encompassing physical, mental, social, and spiritual aspects (9). Studies conducted among US nurses specializing in kidney diseases underscored the need for hospice and palliative care for progressive terminal kidney disease patients, suggesting the importance of holistic, individualized care and family support through a multidisciplinary approach and effective communication (10,11). A previous study emphasized the particular importance of socio-psychological and spiritual care in providing holistic care for terminal kidney disease patients and their families (9).

All human beings have spiritual needs (SNs) (12), which refer to spiritual longing in a positive or negative sense (13), reflecting the spiritual aspect of human being, who seek to find meaning through interpersonal, intrapersonal, and transcendent relationships (14).

Despite the high prevalence of unmet SNs, little research has been done on the status of SNs among terminally ill patients with non-cancer diseases, including CKD, or on guidelines for clinical practice related to spiritual nursing interventions. In 2016, cancer was still the top single cause of death in Korea (7), but deaths from non-cancer chronic diseases, including cerebrovascular diseases and cardiac disorders, are becoming increasingly common, to the point that they are collectively surpassing the number of cancer-caused deaths (1). However, hospice and palliative care services are still almost absent for

# KJ**Ḧ́ÞC**

non-cancer patients.

CKD and other non-cancer chronic disease patients often have more severe physical and cognitive disabilities than cancer patients in the terminal stage of their illnesses, resulting in a higher level of dependency and a need for longer-term care (15). The family caregivers of these patients therefore suffer mentally and physically from a lack of time for self-care and interruptions in work and daily life (16). This situation has negative impacts on both the patient and their family; furthermore, family members experience significant impacts on their quality of life not only while the patient is alive, but even after the patient's death, as they may continue to suffer physically, psychologically, socially, and spiritually (10,11). Family caregivers may also share the patient's experience of illness, experiencing the same distress and burn-out as the patient (17). In Korea, where family ties are relatively strong, the family members of severely ill patients usually want to be actively involved in the treatment process, rather than being passive observers (18). Previous research has shown that family members take on a large part of caregiving-and may even be completely responsible for caregiving-which means that having a family member diagnosed with a terminal illness affects the entire family, not just the patient (17). Therefore, a priority in hospice and palliative care should be identifying the needs of the family caregivers involved in patient care.

Upon this background, this study aims to provide foundational data by obtaining insights into the SNs of progressive terminal CKD patients and their family caregivers and by the identifying factors that influence those needs, in order to help develop spiritual nursing intervention measures to support holistic caregiving for non-cancer patients in hospice and palliative care and their families.

#### 2. Purpose

The purpose of this study was to conduct a comparative analysis of the SNs of progressive stage 4 CKD patients and their family members, and to investigate the factors that affect those needs. More specifically, the goals were:

1) To identify differences in the SNs of patients and their family members according to their general characteristics;

2) To identify differences in SNs between patients and their family members;

## KJHĊ

3) To identify the factors that affect the SNs of patients and their family members.

### **METHODS**

#### 1. Design

This study was an exploratory comparative survey aimed at understanding the factors that influence the SNs of progressive terminal kidney disease patients and their family members.

#### 2. Participants and data collection

The study was approved by the Institutional Review Board of S University (2018012HR). Upon approval, participants were selected from progressive terminal CKD patients receiving outpatient treatment and hemodialysis at the nephrology department of a secondary hospital in Seoul and their family members, who indicated that they understood the purpose of the study and voluntarily consented to participate. The detailed criteria for participant selection were as follows: 1) patients diagnosed with stage 4+ CKD who were receiving hemodialysis and their family caregivers (main caregivers); 2) those who provided written informed consent to participate in the study; and 3) those who had the ability to understand and answer the survey questions. CKD was defined based on the 2012 Kidney Disease Improving Global Outcomes guideline as including patients with a glomerular filtration rate (GFR) of 29 mL/min or lower (3,19). The GFR is a measure of the kidneys' ability to remove nitrogenous waste over a certain period of time, and is known as the best method to evaluate kidney function (3,19).

The independent-samples t-test was the main statistical test used in this study, and the number of participants was calculated using G\*Power, with a medium effect size of 0.5 (Cohen, 1988), a significance level of 0.05, and a statistical power of 0.80. The required number of participants was 64 for each group, totaling 128, but the actual survey was administered to 150 patients and 100 family caregivers, considering the possibility of attrition. In total, 190 survey responses (102 from patients, 88 from family caregivers) were used in the final analysis out of 218 collected surveys, after the exclusion of 28 responses with missing values.

#### 3. Research tools

This study used the Spiritual Interests Related to Illness Tool (SpIRIT) measure developed by Taylor, which is a self-reporting survey tool that measures the degree of spiritual interests related to illness from the perspective of care recipients and can be administered to both patients and their family members (12). The tool consists of a total of 42 questions, including 9 items on relating to God (RG), 6 items on loving others (LO), 6 items on receiving love and spiritual support (RLSS), 5 items on finding meaning (FM), 5 items on maintaining positive perspective (MPP), 4 items on preparing for death (PD), and 3 items on asking "why?" (AW). The answers are evaluated using a 5-point Likert scale, with higher scores implying higher SNs.

Cronbach's alpha of the SpIRIT measure was 0.963 (patients: 0.961, family caregivers: 0.964) in this study. Cronbach's alpha of the sub-dimensions of SNs in the original tool were as follows: RG, 0.942; LO, 0.830; RLSS, 0.828; FM, 0.778; MPP, 0.818; PD, 0.815; RBL, 0.671; and AW, 0.955. The corresponding values calculated in this study were: RG, 0.948; LO, 0.762; RLSS, 0.826; FM, 0.770; MPP, 0.798; PD, 0.841; RBL, 0.741; and AW, 0.616.

### 4. Data analysis

The data analysis was carried out as follows: participants' characteristics were presented using descriptive statistics (frequency, percentage, average, and standard deviation), and the significance of between–group differences was tested using the chi–square test and the independent t–test. Differences in SNs based on participants' general characteristics were analyzed using the independent t–test and 1–way analysis of variance, and the Scheffé post–hoc test was used. The average score and standard deviation were calculated for each question, and the independent t–test was used to identify significant differences in SNs between patients and their family caregivers. Multiple regression analysis with dummy variables was conducted to identify the factors that affected the SNs of patients and their family caregivers.

Multiple regression analysis with dummy variables is a method used to analyze the relationship between independent variables and dependent variables when the independent variables are on a nominal or ordinal scale (20). In this study, the following categorical variables were analyzed: age (40s, 50s, 60s, and 70s and older), gender (male, female), marital status (never married, married, separated/divorced, widowed/bereaved), education ( $\leq$  middle school,  $\leq$  high school,  $\geq$  university), living status (home, facility), perception of financial resources as sufficient (yes, no), being religious (yes, no), the primary spiritual caregiver (family member, healthcare provider, clergy), and

		Patients (N=102)	Family members (N=88)	
Characteristics	Categories	N (%) or mean±SD	N (%) or mean±SD	P*
Sociodemographic characteristics				
Age (yr)	Years	63.61 ± 12.50	57.09±13.74	0.001+
	<50	10 (9.8)	21 (23.9)	0.001
	50~59	26 (25.5)	17 (19.3)	
	60~69	33 (32.4)	39 (44.3)	
	≥70	33 (32.4)	11 (12.5)	
Gender	Male	60 (58.8)	21 (23.9)	< 0.001
	Female	42 (41.2)	67 (76.1)	
Marital status	Never married	12 (11.8)	15 (17.0)	< 0.001
	Married	59 (57.8)	68 (77.3)	
	Separated/divorced	13 (12.7)	0 (0.0)	
	Widowed/bereaved	18 (17.6)	5 (5.7)	
Education	Middle school	37 (36.3)	19 (21.6)	0.003
	High school	46 (45.1)	34 (38.6)	
	≥University	19 (18.6)	35 (39.8)	
Relationship with patient	Spouse/partner	_	39 (44.3)	-
	Child	-	33 (37.5)	
	Friend/neighbor	-	1 (1.1)	
	Others	-	15 (17)	
Living status	Home	97 (95.1)	_	-
5	Facility	5 (4.9)	-	
Perception of financial resources as	Yes	17 (16.7)	-	_
sufficient	No	85 (83.3)	-	
Religion	No	47 (46.1)	38 (43.2)	0.770
	Yes (Christian, Buddhist,	55 (53.9)	50 (56.8)	0.770
	others)			
The primary spiritual caregiver	Family member	61 (59.8)	49 (55.7)	0.001
. ,	Healthcare provider (nurse, physician)	18 (17.6)	18 (20.5)	
	Clergy	16 (15.7)	19 (21.6)	
Disease-related characteristics				
How distressed are you by your illness (10 scale)		5.77±2.78	6.80±2.55	0.009 <sup>+</sup>
Time spent on caregiving (per week)		-	94.19±63.87	_
Duration of caregiving (mo)		-	29.33±48.63	-
Expected outcomes of the illness <sup>†</sup>	Will be cured	19 (18.6)	24 (27.9)	0.262
1	Will live for a long time	57 (55.9)	36 (41.9)	51202
	Will live for a short time and not	13 (12.7)	13 (15.1)	
	be cured	··-·· /	····/	
	Don't know	13 (12.7)	13 (15.1)	

\*Chi-square test, <sup>†</sup>t-test, <sup>†</sup>Excluding missing data (family=2).

relationship with patient (spouse/partner, child, friend/neighbor, other). These were considered as independent variables for the regression analysis.

### RESULTS

# 1. Sociodemographic and disease-related characteristics of the participants

The average age of the participants was meaningfully different between patients ( $63.61 \pm 12.50$  years) and their family caregivers (57.09±13.74 years) (P=0.001). There were more men among the patients (58.8%) and more women among the family caregivers (76.1%) (P=0.001). In total, 58.8% of the patients and 77.3% of the family caregivers were married, and the 2 groups showed significant differences in the distribution of marital statuses (P<0.001). Education level also differed between the patients and family caregivers, as the plurality (45.1%) of the patients were high school graduates, whereas the plurality (39.8%) of the family participants had attended university (P=0.003). Among the family caregivers, 44.3% were patients' spouses and 37.5% were patients' children. The

Channe at a visting	Catagoria	Patients (N=1	102)	Family membe	ers (N=88)
Characteristics	Categories —	M±SD	P*	M±SD	P*
Age (yr)	<50	155.40±33.30	0.725	152.29±21.00	0.243
	50~59	145.50±26.85		168.76±18.73	
	60~69	151.52±25.08		159.31 ± 28.77	
	≥70	150.88±25.04		161.64±23.32	
Gender	Male	148.40±28.04	0.420 <sup>+</sup>	159.14±23.70	0.899 <sup>+</sup>
	Female	152.67±23.31		159.94±25.43	
Marital status	Never married	153.25±36.88	0.861	153.25±36.88	0.084
	Married	148.90±25.37		148.90±25.37	
	Separated/divorced	154.85±21.20		154.85±21.20	
	Widowed/bereaved	148.83±25.31		148.83±25.31	
Education	≤Middle school	153.86±26.37	0.497	149.89±29.98	0.074
	≤High school	147.00±25.65		158.91 ± 24.49	
	≥University	150.58±27.37		165.91 ± 20.83	
Relationship with patient	Spouse/partner	-	-	158.97±29.18	0.928
	Child	-		160.15±21.46	
	Friend/neighbor	-		176.00	
	Others	-		159.80±21.58	
_iving status	Home	149.59±26.49	0.336 <sup>+</sup>	-	-
5	Facility	161.20±16.48		-	
Perception of financial	Yes	159.88±26.14	0.093 <sup>+</sup>	-	-
resources as sufficient	No	148.21 ± 25.88		-	
Religion	No	139.02±25.03	< 0.001 +	151.13±25.27	0.004 <sup>+</sup>
5	Yes (Christian, Buddhist, others)	159.67±23.37		166.30±22.73	
The primary spiritual	Family member <sup>a</sup>	149.75±26.37	0.503	154.19±25.73	< 0.001
caregiver	Healthcare provider (Nurse, Physician, others) <sup>b</sup>	150.71±24.00		151.93±17.49	a, b <c⁺< td=""></c⁺<>
	Clergy <sup>c</sup>	158.40±24.03		179.22±19.90	
Expected outcomes of the	Will be cured	159.68±26.03	0.213	169.79±28.18	0.080
illness <sup>§</sup>	Will live for a long time	149.18±25.89		154.61 ± 25.61	
	Will live for a short time and not be cured	150.54±28.01		162.69±18.88	
	Don't know	140.15±23.92		152.23±18.29	
piritual needs		150.16±26.16		159.75±24.89	-2.578 (0.01

\*Analysis of Variance, <sup>†</sup>t-test, <sup>†</sup>Scheff test, <sup>§</sup>Excluding missing data (family=2).

overwhelming majority (95.1%) of the patients lived at home, while 4.9% lived in a facility. Most patients did not perceive

themselves as having sufficient financial resources 83.3%, while only 16.7% perceived themselves as having sufficient financial

	Patients	(N=102)	Family mem	bers (N=88)		Total (l	V=202)
Items —	Mean	SD	Mean	SD	P*	Mean	SD
Sub-dimension 1. Relating to God (RG)							
29. Remember how God has guided and helped me	3.26	1.19	3.58	1.21	0.072	3.41	1.20
30. Feel that there is a God out there looking after me	3.34	1.20	3.56	1.21	0.224	3.44	1.21
31. Know God's will	3.27	1.05	3.52	1.11	0.117	3.39	1.09
32. Accept that God is in control of my illness.	3.19	1.23	3.32	1.13	0.446	3.25	1.18
28. Believe that God has healed or will heal me	3.29	1.19	3.52	1.27	0.202	3.40	1.23
36. Pray privately	3.25	1.16	3.75	1.05	0.002	3.48	1.14
27. Get right with God	3.52	1.12	3.76	1.05	0.129	3.63	1.09
37. Read scripture or other materials that nurture my spirit.	3.18	1.18	3.53	1.12	0.035	3.34	1.17
38. Have quiet time to reflect or meditate	3.56	1.08	3.85	0.89	0.041	3.69	1.00
Sub total	3.32	0.96	3.60	0.95	0.044	3.45	0.96
Sub-dimension 2. Loving others (LO)							
9. Try to help others	4.03	0.68	3.99	0.72	0.689	4.01	0.70
6. Make the world a better place	3.75	1.08	4.07	0.87	0.030	3.90	0.99
7. Return others' kindnesses	4.05	0.69	4.25	0.55	0.030	4.14	0.64
13. Be appreciated by others	3.68	0.89	3.72	0.88	0.760	3.69	0.89
8. Protect my family from seeing me suffer	3.78	0.96	3.58	0.99	0.151	3.69	0.98
10. Get right with others (e.g., forgive or be forgiven)	4.16	0.67	4.26	0.73	0.307	4.21	0.70
Subtotal	3.91	0.57	3.98	0.55	0.400	3.94	0.56
Sub-dimension 3. Receiving love and spiritual support (RLS	SS)						
<ol> <li>Receive prayer or a religious ritual (e.g., communion) from a religious leader</li> </ol>	3.25	1.18	3.61	1.06	0.025	3.42	1.14
35. Listen to religious programs or music (e.g., on TV or radio)	3.05	1.21	3.33	0.91	0.070	3.18	1.09
34. Attend a spiritual meeting or religious service (e.g., at a church, mosque, or temple)	3.00	1.13	3.34	1.12	0.039	3.16	1.14
11. Become more comfortable about receiving care from other people	3.62	0.90	3.78	0.79	0.182	3.69	0.86
12. Know that others are praying or thinking positive thoughts for me	3.76	0.96	3.97	0.85	0.130	3.86	0.91
14. Be with others I consider to be family	4.05	0.71	4.18	0.77	0.216	4.11	0.74
Subtotal	3.45	0.74	3.70	0.69	0.018	3.57	0.72
Sub-dimension 4. Finding meaning (FM)							
26. Become aware of positive things that have come with this illness	3.77	0.92	4.11	0.72	0.005	3.93	0.85
24. Try to make life count	3.96	0.86	4.25	0.75	0.015	4.09	0.82
23. Get beyond asking "why me (us)?"	3.49	0.91	3.56	0.95	0.622	3.52	0.92
25. Sense that there is a reason for my being alive now	3.89	0.94	4.17	0.65	0.018	4.02	0.83
22. Realize that there are other people who are worse off than me	3.61	0.88	3.68	0.86	0.561	3.64	0.87
Subtotal	3.75	0.66	3.95	0.55	0.020	3.84	0.62
Sub-dimension 5. Maintaining positive perspective (MPP)							
1. Keep a positive outlook	4.08	0.86	4.43	0.74	0.003	4.24	0.83
2. Have hope that I will get well	3.95	0.94	4.40	0.77	< 0.001	4.16	0.89

Table 3. Mean Differences between the 2 Groups on the Spiritual Needs.

		lable 3. Contin	ueu.				
ken a	Patients	(N=102)	Family mem	bers (N=88)	D.,	Total (I	N=202)
ltems —	Mean	SD	Mean	SD	– P*	Mean	SD
Sub-dimension 5. Maintaining Positive Perspective (MPP)							
5. Have faith within myself	3.95	0.99	4.28	0.80	0.012	4.11	0.92
3. Count my blessings	3.71	0.97	4.16	0.83	0.001	3.92	0.93
4. Tell others about the good things in my life	3.46	0.98	3.66	0.99	0.169	3.55	0.99
Subtotal	3.83	0.71	4.19	0.59	< 0.001	3.99	0.68
Sub-dimension 6. Preparing for Death (PD)							
40. Balance thought about dying with hoping for health	3.61	1.01	3.84	0.91	0.098	3.72	0.97
41. Know that there will be a purpose for my death, whenever it happens	3.40	1.07	3.73	1.01	0.034	3.55	1.06
39. Make sure my personal business is in order	3.66	0.95	4.01	0.72	0.004	3.82	0.87
42. Think about what happens after death in the "afterlife"	3.08	1.17	3.11	1.01	0.826	3.09	1.10
Sub total	3.44	0.87	3.67	0.75	0.048	3.55	0.82
Sub-dimension 7. Reevaluating Beliefs and Life (RBL)							
16. Think about whether my beliefs about God are correct	3.28	1.18	3.64	1.11	0.036	3.45	1.16
15. Review what I believe	3.83	0.81	4.02	0.88	0.125	3.92	0.85
20. Reevaluate my life	3.69	0.89	3.89	0.82	0.111	3.78	0.86
<ol> <li>Think about what it means to live spiritually (e.g., to have faith, to forgive)</li> </ol>	3.34	1.05	3.57	1.00	0.134	3.45	1.03
Sub total	3.54	0.72	3.78	0.74	0.024	3.65	0.74
Sub-dimension 8. Asking "why?" (AW)							
19. Think about the unfairness of what has been happening	3.36	0.94	3.51	0.88	0.266	3.43	0.92
17. Ask "why?" questions (e.g., Why me? Or why not me? Or why did I deserve this?)	3.23	0.94	3.45	0.95	0.097	3.33	0.95
21. Find helpful explanations for why this illness happened to me	3.76	0.98	3.80	0.85	0.818	3.78	0.92
Sub total	3.45	0.70	3.59	0.69	0.180	3.51	0.70
Total	3.58	0.62	3.80	0.59	0.011	3.68	0.62

Table 3. Continued.

\*t-test.

resources (16.7%). Slight majorities of the patients and family caregivers (53.9% and 56.8%, respectively) were religious (P=0.691). Patients ranked their primary spiritual caregiver in the order of family members (59.8%), healthcare providers (17.6%), and clergy (15.7%), while the corresponding order for family members was family members (55.7%), clergy (21.6%), and healthcare providers (20.5%) (Table 1).

The level of distress felt by family members was more severe, at  $6.80\pm2.55$  points on a 10-point scale, than the level of pain felt by patients ( $5.77\pm2.78$  points) (P=0.009). Family caregivers took care of patients for  $94.19\pm63.87$  hours weekly and had been taking care of the patients for  $29.33\pm48.63$  months. When asked about the prognosis of the disease, 55.9% of the

patients thought they would live with the condition for an extended period, while 18.6% of them expected a complete recovery and 12.7% did not expect a complete recovery even though the symptoms could be treated temporarily. The corresponding proportions of family members' responses were 41.9%, 27.9%, and 15.1%, respectively, but the results did not show a statistically significant difference (P=0.262) (Table1).

# 2. Differences in SNs by participants' general characteristics

SNs were higher among patients and family members who were religious than those who were not (P < 0.005). Family members who selected clergy as their primary spiritual care–

giver had the highest SNs, followed by those who selected family members or health care providers (P < 0.001) (Table 2).

SNs did not show significant differences in either group according to age, gender, marital status, education, relationship with the patient, living status, perception of having sufficient financial resources, and expected outcomes of the illness (P > 0.05) (Table 2).

# 3. Mean differences between patients and family caregivers in SNs

The average score for SNs was 3.68 ( $\pm$ 0.62), with a statistically significant difference between patients and their family caregivers (3.58 $\pm$ 0.62 and 3.80 $\pm$ 0.59, respectively) (P=0.011). The highest SNs were found for the MPP sub-dimensions (3.99 $\pm$ 0.68 points), followed in order by LO (3.94 $\pm$ 0.56 points), FM (3.84 $\pm$ 0.62 points), AW (3.68 $\pm$ 0.62 points), RBL (3.65 $\pm$ 0.74 points), RLSS (3.57 $\pm$ 0.72 points), PD (3.55 $\pm$ 0.82 points), and RG (3.45 $\pm$ 0.96 points) (Table 3).

The average level of SNs for each item was significantly different (P<0.05) between the 2 groups in 6 of the 8 sub-dimensions, with the following average scores for patients versus family caregivers in each sub-dimension:  $3.32\pm0.96$  versus  $3.60\pm0.95$  in RG,  $3.45\pm0.74$  versus  $3.70\pm0.69$  in RLSS,  $3.75\pm0.66$  versus  $3.95\pm0.55$  in FM,  $3.45\pm0.74$  versus  $3.70\pm0.69$  in MPP,  $3.44\pm$  0.87 versus  $3.67\pm0.75$  in PD, and  $3.54\pm0.72$  versus  $3.78\pm$  0.74 in RBL. The remaining two sub-dimensions of LO and AW did not show meaningful differences between the 2 groups (P<0.05) (Table 3).

#### 4. Factors influencing participants' SNs

Multicollinearity was detected in the variable relating to expected outcomes of the illness, which was therefore excluded from the analysis (Table 4). The variance inflation factor values of all other independent variables in this study were 10.0 or lower, indicating no issues with multicollinearity. The Durbin–Watson values were close to 2 in both groups, with 2.215 for patients and 2.218 for family members, implying that the regression model was appropriate for explaining the dependent variables without issues related to autocorrelation. The coefficients of determination, which represent the explanatory pow– er of independent variables, were  $R^2$  (adj.  $R^2$ )=0.235 (0.102), F=1.765, P=0.053 for the patients and  $R^2$  (adj.  $R^2$ )=0.357

## KJĦĊ

(0.223), F=2.666, P=0.00 for the family caregivers (Table 4).

The estimated multiple regression equation for the SNs of the 2 groups were as follows: SNs=-23.650\*Religion (No)+172.341 for patients and SNs=-24.384\*Education (Mid-dle school)+184.794 for family caregivers. The SNs of patients were negatively influenced by not being religious ( $\beta$  =-0.453, t= -3.888, P<0.001), while having achieved only a middle school education had a negative effect on SNs in family members ( $\beta$  = -0.405, t=-3.228, P=0.002) (Table 4).

### DISCUSSION

This study investigated the level of SNs in patients with progressive CKD and their family caregivers, as well as the factors affecting SNs, mainly by comparing results between patients and their family caregivers. The following discussion elaborates upon the outcomes of the comparison between the 2 groups.

This study measured the level of SNs of 102 CKD patients and 88 family members using SpIRIT, a tool developed by Taylor in 2006 (12). The SNs of patients and family caregivers were meaningfully different. This is not in line with the results of Cho's 2008 study, in which 164 cancer patients and 178 family members participated and no statistically significant differences were found between the 2 groups (14).

The results of the present study are similar to those of the 2008 study conducted by Park, who analyzed 50 cancer patients and 103 family members and found that the degree of SNs of the cancer patients  $(3.35 \pm 0.94)$  was lower than that of their family members  $(3.72 \pm 0.76)$  (21). In the present study, the SN scores of progressive CKD patients  $(3.58\pm0.62)$  were lower than those of their family caregivers  $(3.80 \pm 0.59)$ . This discrepancy may be caused by the fact that for many patients with chronic conditions, their doctors have decided that nothing more can be done medically, and family members are faced with the realization that nothing can be done other than keeping them comfortable at home (6,22). In this situation, family members shoulder the burden and face the responsibility of looking after the patients, doubling their familial duties. They are often forced to quit their jobs to take care of the terminally ill family member, which affects their physical, mental, social, and economic activities (17) and inflicts major distress in their lives (23). Our findings show that patients with non-cancer

Vol. 23	•	No. 1	•	2020
101, 25		1.0.1		2020

KJ <b>Ḧ́ÞC</b>	
----------------	--

			Patients (N=102)				Fa	Family members (N=88)	38)	
Predictors	Non-sta coef	Non-standardized coefficients	Standardized coefficients	٩	~IF*	Non-sta coeff	Non-standardized coefficients	Standardized coefficients	٩	ΛF⁺
	*	SE⁺	(8)			*	SE⁺	(β)		
Constant	172.341	12.462	T	<0.001	I	184.794	11.894		<0.001	I
Age D1 (<50)	-2.952	13.484	-0.034	0.827	2.669	-8.313	8.964	-0.143	0.357	2.669
Age D2 (50~59)	824	7.725	-0.014	0.915	1.881	0.960	8.062	0.015	0.906	1.852
Age D3 (60~69)	-3.398	6.791	-0.061	0.618	1.676	I	I	I	I	I
Age D4 (≥70)	I	I	I	I	I	4.244	8.073	0.057	0.601	1.303
Gender D2 (female)	-2.783	3.237	-0.105	0.392	1.685	0.548	3.027	0.019	0.857	1.217
Marital status D1 (never)	8.530	11.597	0.106	0.464	2.318	-9.407	8.536	-0.143	0.274	1.883
Marital status D3 (separated/divorced)	6.630	8.044	0.085	0.412	1.195	I	I	I	I	I
Vlarital status D4 (widowed/bereaved)	2.618	7.515	0.038	0.728	1.363	-0.257	11.743	-0.002	0.983	1.351
Education D1 (middle school)	I	I	I	I	I	-24.384	7.554	-0.405	0.002	1.766
Education D2 (high school)	-4.162	3.042	-0.159	0.175	1.522	-5.805	3.047	-0.228	0.061	1.609
Education D3 (≥university)	-2.355	2.814	-0.106	0.405	1.793	I	I	I	I	I
Living status D2 (facility)	11.031	11.912	0.091	0.357	1.098	I	I	I	I	I
Perception of financial resource as sufficient D2 (no)	-11.798	7.342	-0.169	0.112	1.243	I	I	I	I	I
Religion D2 (no)	-23.650	6.083	-0.453	< 0.001	10.526	-8.934	5.350	-0.179	0.099	1.284
The primary spiritual caregiver D1 (family)	7.209	9.446	0.136	0.447	3.561	-15.741	8.691	-0.316	0.074	3.407
The primary spiritual caregiver D2 (healthcare provider)	-1.916	10.558	-0.028	0.856	2.690	-15.424	9.183	-0.251	0.097	2.508
The primary spiritual caregiver D3 (dergy)	4.350	10.852	0.061	0.690	2.586	4.016	9.414	0.067	0.671	2.742
Relationship with patient D2 (child)	I	I	I	I	I	-0.523	3.931	-0.020	0.894	2.648
Relationship with patient D3 (friend/neighbor)	I	I	I	I	I	8.798	7.591	0.113	0.250	1.065
Relationship with patient D4 (other)	I	I	I	I	I	2.582	2.098	0.157	0.222	1.820
Statistics		R <sup>2</sup> =(	R <sup>2</sup> =0.235, Adj R <sup>2</sup> =0.102				$R^{2}=$	R <sup>2</sup> =0.357, Adj R <sup>2</sup> =0.223	~	
		F=1.	F=1.765, P=0.053				F=2	F=2.666, P=0.003		
		Durt	Durbin-Watson' d=2.215	15			Dur	Durbin-Watson' d=2.218	18	

www.kjhpc.org 35

# KJ**HÞC**

chronic diseases such as progressive CKD and their family caregivers had medium or higher levels of SNs, with especially high needs among family members. A systematic review would be necessary to provide a basis for effective nursing interventions to meet the SNs of patients with non-cancer chronic diseases and their family caregivers.

The SNs of the patient participants in this study were highest in the LO domain, followed by MPP and FM. This precisely mirrors the results reported in Cho's 2008 study (14), implying that love is the single most important factor in times of human crisis and that patients wish to find peace of mind by loving others (10,24). It is necessary to help progressive CKD patients with an unpredictable prognosis transform their roles to form diverse psychological and social relationships capable of meeting their need to love others and to provide psychological support. In contrast, the highest SNs of family members were found for the MPP domain, followed by LO and FM. This result is somewhat different from that reported by Cho's 2008 study, which suggested that family caregivers' SNs were highest in the MPP domain, followed by RLSS and FM (14), but precisely corresponds to the findings of Taylor's 2006 study (12). For family caregivers, maintaining a positive perspective toward the patient and the disease, as well as remaining hopeful for a full recovery, is more important than anything (10,25). Therefore, family caregivers who are not very hopeful about the situation are more likely to be stressed out due to their burden of looking after the patient, failing to effectively cope with and adapt to the situation. Conversely, family caregivers faced with the task of taking care of non-cancer chronic disease patients will be able to cope better with the situation if they continue to maintain a positive mindset and attitude and stay hopeful. Developing a program to reinforce positive thinking and a hopeful mindset among family members through a multidisciplinary approach and sustained research will be necessary at hospice and palliative care sites. The 2014 study conducted by Bull suggested that the loss of physical function and physical pain caused by stage 4 CKD are crucial factors that affect patients' distress, and that collaborative decision-making among patients, family members, and hospice service providers is important for providing effective care. That study particularly emphasized the need for medical staff to provide educational support to family members on beliefs, values, and information

(23). Moreover, an individualized approach is desirable, as medical staff, patients, and family members may all have different SNs (16). Investigating the SNs of non-cancer chronic disease patients and their family members to understand their exact needs should be a high priority when working towards the goal of providing appropriate hospice and palliative care services.

This study found that being religious was a factor that influenced the level of progressive CKD patients' SNs, as not being religious had a negative effect on SNs. For family members, having a middle school education as the highest level of completed education had a negative effect on SNs. This result is similar to the outcome of Park's 2008 study on cancer patients and their family members, in which patients without religious beliefs had lower scores  $(3.65 \pm 50)$  for nursing needs than those with religious beliefs such as Christianity  $(3.93 \pm .45)$  or Buddhism  $(3.90 \pm .58)$  (21), and family members showed significant differences according to their education level, with  $4.09 \pm 0.35$ for those with at least a university education,  $4.04 \pm 37$  for those with a high school education or less, and  $3.85 \pm 0.46$  for those with a middle school education or less. As such, religious patients have higher SNs, which implies that it is necessary to develop treatment and nursing intervention programs to meet their SNs. Proper nursing interventions should be provided to meet patients' actual needs by understanding the perceptions of progressive chronic CKD patients and their family members towards SNs, as well as the factors that influence those perceptions. In order to provide ideal care for terminally ill patients and their family members, a strategic end-stage care plan should be based on a collaborative relationship with patients and their family members. In light of this, the outcomes of this study may serve as useful foundational data for effectively evaluating the SNs of terminally ill non-cancer patients and their family members and developing corresponding nursing interventions.

This study mainly focused on understanding differences in SNs between progressive CKD patients and their family caregivers, as well as factors influencing the level of SNs. The number of participants needed at the point of analysis was different from the number decided upon at the study design stage. More participants would be desirable to study the factors that influence the SNs of patients and their family members.

Hopefully, the outcomes of this study will contribute to providing integrated hospice and palliative care interventions through additional research and multidisciplinary intervention programs for non-cancer chronic patients and their family members based on the differences in SNs and the factors influencing SNs that were identified in this study.

### SUPPLEMENTARY MATERIALS

Supplementary materials can be found via https://doi.

org/10.14475/kjhpc.2020.23.1.27.

### ACKNOWLEDGEMENTS

We would like to thank Eunjeong Kim, M.D. Division of Nephrology, Department of Internal Medicine, and Eunsook Han, M.S. RN, Department of Internal Medicine, Sahmyook Medical Center, Seoul, South Korea who supported data collection for this study.

### REFERENCES

- 1. Cha ES, Lee JW, Lee KW, Hwang YJ. Illness experiences and palliative care needs in community dwelling persons with cardiometabolic diseases. Korean J Hosp Palliat Care 2019;22:8–18.
- 2. Shin JY, Yoon SJ, Kim SJ, Lee ES, Koh SJ, Par JN. A qualitative study of physicians' perspectives on non-cancer hospice-palliative care in Korea: focus on AIDS, COPD and liver cirrhosis. Korean J Hosp Palliat Care 2017;20:177–87.
- 3. Kim HW. Prevalence and related factors of chronic kidney disease in Korean adults [master's thesis]. Seoul: Korea Univ.; 2017. Korean.
- 4. ESRD Registry Committee; The Korean Society of Nephrology. Current status of renal replacement therapy in Korea [Internet]. Seoul: The Korean Society of Nephrology: 2015 [cited 2017 Mar 20]. Available from: http://www.ksn.or.kr/rang\_board/inc/download.php? nocount=1 &code=sinchart&num=1742.
- 5. Korea Center for Disease Control and Prevention. 2014 National Health and Nurtrition Survey Results Announced [Internet]. Sejong: Ministry of Health and Welfare: 2015. [cited 2015 Oct 12]. Available from: http://www.mw.go.kr/front\_new/al/sal0301vw.jsp?PAR\_MENU\_ ID=04&MENU\_ID=0403&CONT\_SEQ=326126&page=1.
- 6. Wasylynuk BA, Davison SN. Palliative care in patients with advanced chronic kidney disease. CANNT J 2015;25:28-32.
- 7. Choi YS, Kim HS. Hospice medical guideline, non-cancer diseases. Korean J Hosp Palliat Care 2010;13:69-75.
- 8. Canadian Institute for Health Information. Canadian organ replacement register annual report: treatment of end-stage organ failure in Canada, 2004 to 2013 [Internet]. Ottawa: Canadian Institute for Health Information: c2015 [cited 2015 Apr 21]. Available from https://secure. cihi.ca/free\_products/2015\_CORR\_AnnualReport\_ENweb.pdf.
- 9. Gwak JH. A research of the spiritual well-being and spiritual needs of HIV/AIDS patients. Korean J Hosp Palliat Care 2009;12:14-9.
- 10. Oarde K. Palliative care education in end-stage renal disease patients undergoing hemodialysis [dissertation]. Arizona: Arizona Univ.; 2017. English.
- 11. Montoya V. Advanced practice nurses and end-of-life care for patients with progressive chronic kidney disease and end stage renal disease. Nephrol Nurs J 2017;44:256–9.
- 12. Taylor EJ. Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. Oncol Nurs Forum 2006;33:729–35.
- 13. Taylor EJ. Spiritual needs of patients with cancer and family caregivers. Cancer Nurs 2003;26:260-6.
- 14. Cho JH. Spiritual needs of family caregivers of patients with cancer [master's thesis]. Seoul: Yonsei Univ.; 2008. Korean.
- 15. Lee HN, Lee JE. A time study of nursing activities by home care nurses for non-cancer terminal patients. J Korean Acad Soc Home Care Nurs 2019;26:180-8.
- 16. Lee JW. End-of-life care needs of community-dwelling non-cancer patients and family caregivers [master's thesis]. Seoul: Catholic Univ.; 2018. Korean.
- 17. Kang KA, Choi YS, Kim YJ. Reliability and validity of an instrument assessing spiritual needs of families of terminal cancer patients. Korean J Hosp Palliat Care 2018;21:144–51.
- 18. Kim HC, Kim ES, Park WH. Needs of patients and their families in hospice care unit. Korean J Hosp Palliat Care 2007;10:137-44.
- 19. Harrison K. Watson S. Palliative care in advanced kidney disease: a nurse-led joint renal and specialist palliative care clinic. Int J Palliat Nurs 2011;17:42-6.
- 20. Noh KS. The proper methods of statistical analysis for dissertation: SPSS & AMOS. 2nd ed. Seoul: Hanbit Publishing Network: 2019. p. 230–40.
- 21. Park CS. The analysis on the recognition and nursing need of hospice in the cancer patient and family [master's thesis]. Seoul: Hanyang

Univ.; 2008. Korean.

- 22. Jeong DJ. A study on spiritual care of the terminally ill [master's thesis]. Daejeon: Mokwon Univ.; 2001. Korean.
- 23. Bull R, Youl L, Robertson IK, Mace R, Challenor S, Fassett RG. Pathways to palliative care for patients with chronic kidney disease. J Ren Care 2014;40:64–73.
- 24. Sedgewick J, Noble H, Ho TM, Kafkla T, Van Waeleghem JP. CE: continuing education article. Integration of palliative care for patients with stage 5 chronic kidney disease. J Ren Care 2010;36:218–26.
- 25. Choi BR. The relationship between hope and post-traumatic growth in family caregivers of patients with cancer: focusing on the mediated effect of family function [master's thesis]. Seoul: Sangmyung Univ.; 2018. Korean.