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The Spirituality in Caregivers and Families With Chronic Patients: Psychometric of Caregiver's Spiritual Empowering Scale

Leila Nikrouz¹, Fatemeh Alhani^{1*}, Abbas Ebadi², Anooshirvan Kazemnejad³

Abstract

Objectives: High tension is the leading cause of the increased risk of mortality among family caregivers (FCGs), resulting in inadequate care and abandonment of the patient. Spirituality promotion is a sense of mastery and control and strength to endure the stressors of illness. To the best of our knowledge, no tool is available for investigating the current spiritual state of the FCG and identifying the need for spiritual intervention in Iran. Therefore, the present study aimed to identify the level of independence of patients with chronic disease and to explore the concept of spirituality and psychometric of related scale, namely, caregiver's spiritual empowering scale (CSES).

Materials and Methods: This study used a multiphase mixed-method approach and was conducted from June 2016 to August 2018 in the southwestern region of Iran. The cross-sectional surveys of activities of daily living (ADL) and instrumental activities of daily living (IADL) were conducted on people with chronic diseases ($n = 389$) in the first phase. In the second phase, the exploratory sequential mixed method was applied for content analysis study ($n = 26$) and psychometric of CSES in FCG ($n = 395$).

Results: The caregivers' age was within the range of 17-74 years (42 Mean \pm 12SD). Based on the results of ADL IADL, 87% and 99.5% of patients were dependent or in need of help. In the qualitative study phase, four main categories emerged in the context of "Empowering spirituality". The reliability and validity of CSES including 12 items loaded one a single factor were confirmed based on the content validity ratio >0.45 , content validity index >0.78 , kappa coefficient >0.75 , impact score > 1.5 , $\alpha = 0.92$, interclass correlation coefficient = 0.91, 95% CI = 0.90-0.92, $r = 0.57$, $P = 0.000$, standard error of the mean = 1.64, and Kaiser-Meyer-Olkin index = 0.94, $P < 0.001$.

Conclusions: In general, spiritual empowerment is essential as a low-cost and effective method in increasing the dependence of people with chronic diseases and the risk of burnout in FCG. Accordingly, the CSES is considered a valid and reliable instrument for measuring the status of empowerment spirituality in informal caregivers and the effectiveness of interventions.

Keywords: Family caregiver, Empowerment, Spirituality, Chronic disease, Psychometric, Caregiver's spiritual empowering scale

Introduction

According to the World Health Organization (WHO), chronic disease is defined as being of long duration and generally slow in progression (1). Nearly half (approximately 45% or 133 million) of all Americans suffer from at least one chronic disease (2). In 2016, non-communicable diseases killed 287 thousand people in Iran. In addition, 6.5 million years of life lost and 8.2 million years lived with disability, demonstrating the dramatic sign of the emergence of non-communicable diseases (3). However, addressing chronic disease is a major challenge for healthcare systems around the world. One characteristic of chronic diseases is that they often require a long period of supervision, observation, or care (1). It is noteworthy that the epidemiological trend of chronic patients is increasing in the world and in Iran. These patients need continuous care. Therefore, the

participation of patients and family members in care is of necessity. Family caregivers (FCGs) play an instrumental role in the lives of people with chronic disease regarding performing the activities of daily living (ADL) (4).

A FCG is defined as anyone who provides help to one or more ADL or instrumental activities of daily living (IADL) and physical and emotional care to a person with chronic illness or disability. Caregivers differ in their relationships with the client including parents, children, spouses, as well as neighbors and friends (5). An FCG, as an invisible workforce for the health system, provides long-term and supportive care for a chronic illness (6). Without FCGs' care, access to high-quality comprehensive, cost-effective medical care is impossible for many individuals who suffer from multiple chronic diseases (7). High tension in a caregiving role is the leading cause of the increased risk of mortality among FCGs (8). Such a pressure

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reduces the continuance of good care, and ultimately, lead to inadequate care and abandonment of the patient (9). Patients' health depends on the ability of FCGs as a significant component of social or family resources (10). Caregivers must have different abilities to respond to the continuation of care for a long process. Thus, it is necessary to provide help for the FCG in coping with the role of caring (11). Caregivers with low levels of spirituality may be at the risk of greater levels of burden, anxiety, and stress (12). Faith is an aspect of self-care for caregivers and helps them to provide hope and strength in order to continue the course of life (11). More precisely, spiritual and religious beliefs and practices often give patients and family members a sense of mastery and control and strength to endure the stressors of illness, and affect their ability to cope with the loss (13). Spirituality and religiosity offer the caregiver and family members' greater emotional, spiritual, and social support (11). Further, high levels of spirituality can serve as a protective buffer from negative mental health outcomes (12). Spirituality is not separate from the somatic or mental aspects of people but provides an integrating power. Furthermore, it affects moods, motivations, and behaviors (14) and leads to hope and less perceived stress, and ultimately, contributes to increased well-being. Moreover, spirituality is directly and positively related to well-being (15). An individual's relationship with Allah is the focal point of Islamic spirituality. Allah is Mighty and Wise and a source of all perfections and His presence is evident for believers. These references support the proposition that Allah is always present and can be called upon in times of threat. Additionally, it is believed that Allah provides security and protection in times of danger (16). A fundamental issue in the empowering process is the formation of a trusting relationship, and as a result, caregivers feel that they are not being abandoned or left alone in the caring process (17). In the Islamic view, biological, psychological, and social dimensions cannot function properly or reach their maximum capacity without the spiritual dimension (18). Therefore, spirituality is a necessary dimension for having a comprehensive perspective in order to provide proper care to the patient (19). Spirituality has different meanings with respect to the philosophical and cultural context and has a dynamic nature over time (20). Additionally, it is the driving force that acts as a source of inner power based on the meaning and purpose of life (21). According to Islamic thinking, obeying God's orders increases humans' knowledge about their capabilities because they apply a greater source of information (i.e., their creator) (22). Similarly, spiritual health is one of the dimensions of health, and caregivers need adequate spiritual capacity for its promotion. Therefore, the recognition of the concept of spirituality is required for understanding the concept of caregivers' spirituality. According to Islam, the nurse's responsibility in the spiritual aspects of care is as important as other dimensions (23).

Objectives

The purpose of this study was to assess the ability of patients to perform ADL and IADL in order to explore the concept of spirituality and psychometric of the related scale, namely, caregiver's spiritual empowering scale (CSES).

Materials and Methods

The current study was conducted using exploratory sequential multiphase mixed methods including two phases. The researcher designed the quantitative study in the first phase, encompassing a cross-sectional survey, and then in the second phase, exploratory sequential mixed methods started with a qualitative phase, followed by a quantitative phase. A multiphase mixed-method provides a more comprehensive understanding of a research problem. These projects may go back and forth between quantitative, qualitative, and mixed-method studies (24). In the first phase, a cross-sectional study was conducted to assess the ability of patients regarding performing ADL and IADL.

The second phase exploratory sequential mixed method encompassed two stages and the first stage had two steps. In this step, the research team conducted qualitative research by a deep interview with the caregivers in order to explore the concept of spirituality by their caring experience. Data were analyzed by content analysis, and in another step, the obtained data from content analysis built an initial pool. In the second stage, the applied mixed method psychometric included validity, consistency, and reliability.

Setting and Samples

This study was done from June 2016 to August 2018 in different environments including specialized clinics, three community health service center, the hospital, and the home environment of the southwestern region of Iran. In this study, family caregivers with experience in caring for chronic patients were selected. These diseases include myocardial infarction, asthma, stroke, hypertension, diabetes and people undergoing hemodialysis, as common chronic diseases mentioned in the National Document for Prevention and Control of Non-Communicable Diseases 2015-2025 of the Islamic Republic Iran (3). The caregiver was introduced as the main caregiver through the appointments with the patient, family, or the healthcare staff. In the first phase, the ADL and IADL questionnaires were given to 389 patients with chronic diseases who were selected by a purposeful sampling method. In the second phase, 26 caregivers (i.e., 19 FCGs to complete the information gap, three chronic patients, and four nurses) participated in the qualitative study in order to achieve information saturation. As regards the psychometric scale, 10 caregivers and five nurses were involved in checking face validity, 17 expert specialists invented in content validity ratio and content validity index, and 54 caregivers

completed the initial scale in the item analysis process. Finally, 395 caregivers completed the scale, along with the measures of construct validity.

Measures

In the first phase, the ADL and IADL scales were completed to assess participants' daily activities (25). The content validity index was more than 0.82 for both ADL and IADL. In addition, the sensitivity and specificity of ADL and IADL were 0.75 and 0.96, respectively. Further, Cronbach's alpha and interclass correlation coefficient (ICC) were more than 0.75. The overall ADL index ranged from 0 to 14 (0-6, 7-10, and 11-14 for "Cannot do: Dependent", "Needs Help", and "Independent" options, respectively) and that of the IADL questionnaire was in the range of 0-16 (0-8, 9-13, and 14-16 for "Dependent", "Needs Help", and "Independent, respectively).

In the second phase, a structure-free in-depth interview was done in a safe and quiet room with an open question after the warming questions (i.e., "Please describe your experiences about caring for patients") to study and discover participants' experiences. During the interview, caregivers, as the key participants related with the family members, were asked to answer the question "How do you deal with problems in taking care of the patient?" Then, probe questions were used to explore participants' experiences and to deepen the interview. Next, the interview proceeded with targeted questions related to spirituality, followed by an unstructured interview asking "Please describe with more examples about the concept of thanksgiving, when you experience the Lord's grace", God's presence in the favor and meaning of life". Nurses as general participants were asked to explain their experiences about the role of the spirituality of FCGs regarding their care. The patient was asked to explain how the FCGs cared for him. The interviews were accurately recorded and considered as a unit of analysis. This process was continued until reaching data saturation. In addition, interviews were conducted in the local accents of participants and then were typed in Persian and reviewed frequently. After the random confirmation of the text, several interviews with the main participants and the approval of the research group were translated into English and edited by a native translator. The main criterion for the duration of the interview was the tolerance, information, willingness, and agreement of the participants.

In the second phase, the quantitative study was followed by the face and content validity, and item analysis. In the construct validity phase, 395 FCGs were selected by a proposed sampling technique after the researcher's permission and explanations regarding the study purpose. The research tools included demographic information, ADL and IADL scales, and CSES for people with chronic disease.

Further, the inclusion criteria were showing a tendency for participating in research, receiving care for chronic

disease for at least six months. On the other hand, individuals were excluded if they did not complete the questionnaire and received an ADL score of ≥ 11 and an IADL score of ≥ 14 .

Data Analysis

In this cross-sectional study, descriptive and inferential statistics (SPSS, version 16) were applied to analyze data regarding the ability of patients with chronic disease for performing ADL and IADL.

Qualitative Content Analysis Study

Using the approach by Hsieh and Shannon, data analysis started with reading all data repeatedly to achieve immersion and obtain a sense of the whole as one would read a novel. Then, data were read word by word to derive codes by highlighting the exact words from the text to indicate a sense of spirituality in order to capture key thoughts or concepts in the form of the meaning unit by making notes of his or her first impressions, thoughts, and initial analysis. As this process continues, some labels emerge for the codes reflecting the key thought. These often come directly from the text and then become the initial coding scheme. Then, the codes are sorted into categories based on how different codes are related (26).

Validity and Reliability

a. Face Validity

The face validity was assessed on the target group or the key participants considering the difficulty in understanding the items, inaccuracy in the meanings, and inappropriateness, modifying the vagueness of the phrases, and finally, calculating the impact score in quantitative face validity (acceptable, impact score >1.5) (27).

b. Content Validity

In qualitative content validity, all the items of the scale were reviewed with regard to grammar correctness, appropriate usage of words, phrases, and clauses, the proper placement of phrases, and proper scoring by the specialist nurse and psychometric instructors. To determine the content validity index (CVI), 17 items were separately assessed in terms of relevance, clarity, and simplicity on a 4-point Likert-type scale (the acceptable range was CVI >0.78). Furthermore, the SCVI/Ave was calculated based on the average of CVI scores (the acceptable range was >0.9). Moreover, the acceptable content validity ratio was >0.45 for determining the necessity of each item. Eventually, Kappa with a minimum of >0.75 was used to decide on keeping the modified item, and SPSS (version 16.0) was calculated for statistical analyses (28,29).

c. Construct Validity

The KMO index and Bartlett test of sphericity were calculated to indicate the adequacy of data for factor

analysis ($P < 0.001$). In factor analysis, KMO index > 0.9 and a significant Bartlett test ($P < 0.05$) were acceptable. In Varimax rotation, factors loadings > 0.45 were considered suitable (29).

d. Reliability Assessment

The internal consistency of the scale was calculated by Cronbach's alpha. Additionally, reliability was investigated using the test-re-test method and ICC. The 49 FCGs' were asked to re-fulfill the scale in a 2-weeks interval. The acceptable Cronbach's and its minimum acceptable alpha coefficient and ICC values for the new instrument were 0.70 (29).

Trustworthiness

Credibility was controlled through member checking, peer debriefing, and prolonged engagement with the subject matter, two experts performed peer checking. The researcher was engaged with participants to collect data within 15 months from June 2016 to March 2018. In addition, transferability was checked by the 'maximum variation sampling' approach and thick description. Regarding dependability with continuous comparative analysis, the triangulation of data sources through interviews with caregivers, nurses, and chronic patients were considered when studying spirituality in care. In this regard, a careful description of the type of approach to applied content analysis can provide a universal language for health researchers and strengthen the scientific base of the method.

Results

Result of the First Phase (Cross-sectional Study)

In the first step of the study, 389 patients with chronic disease accomplished ADL and IADL scales. Based on the results, patients' age ranged from 12 to 97 years with a mean (standard deviation) of 64.52 (16.25). Furthermore, 223 (56.6%), 297 (75.6%), 229 (58%), and 254 (54.4%) participants were females, married, and illiterate, and lived in the city, respectively. Moreover, 204 (51.6%), 50 (12.7%), 45 (11.4%), 21 (5.3%), 19 (4.8%), 16 (4.1%), and, 15 (3.8%) of them suffered from multi diseases, hypertension, diabetes, Cough variant asthma, asthma,

dialysis, and heart disease, respectively. Recent ADL data showed that more than 87% of people with chronic disease were dependent on or needed help in their daily routine activities. The results further demonstrated that bathing ($n=30$, 7.6% and food ($n=240$, 60.8%) activities were the lowest and highest independent performance, respectively (Table 1).

Regarding IADL, 99.5% of participants were dependent or needed help in performing their daily activities. Additionally, 288 chronic patients (72.9%) were often dependent on caring for food. Similarly, patients often required accurate drug use and had the highest independent functionality ($n=150$, 38%), the details of which are provided in Table 2.

Result of the Second Phase (Exploratory Sequential Mixed Methods)

Demographic Data of the Key Participant in the Qualitative Study

In the first step (the first stage of the study), 28 interviews were conducted, including 19 FCGs (FCGs), 3 chronic patients, and 4 nurses, in order to complete the information gap. Two FCGs were interviewed twice. In general, 42% (8 FCGs), 47% (9 FCGs), 78% (15 FCGs), and 26% (5 FCGs) were males and single, lived with the patient, and had a university education, respectively. In addition, participants were in the age range of 21-60 years ($M_{age} = 40.5$ years) and had education levels varying from illiterate to expert. Based on the obtained data, FCGs with a chronic patient care experience of 6 months to 25 years (7 ± 1.5 years in average) had different roles as the child and spouse, as well as the grandson of both genders and the brides of the families (Table 3).

Qualitative Content Analysis Study

By frequently reviewing the data, four main categories emerged in the context of the "empowering spirituality" concept in the qualitative study phase, including "monotheistic cognition", "divine love", "empowering worshiping ritual", and "transcendental care" (Figure 1).

"Empowering spirituality" emerged from four categories in data analysis, including "monotheistic cognition", "divine love", "empowering worshiping ritual",

Table 1. ADL of People With Chronic Disease Under Study

ADL	Cannot Do, n (%)	Needs Help, n (%)	Independent, n (%)
1. Eating	38 (6.9%)	117 (29.6%)	240 (60.8%)
2. Dressing	53 (13.4%)	199 (50.4%)	143 (36.2%)
3. Walking	95 (24.1%)	249 (63.2%)	50 (12.7%)
4. Grooming	83 (21%)	227 (57.5%)	85 (21.5%)
5. Bathing	118 (30%)	245 (62.3%)	30 (7.6%)
6. Transferring Bed/chair	59 (15.1%)	167 (42.6%)	166 (42.3%)
7. Toileting	68 (17.3%)	232 (59%)	93 (23.7%)

Note. ADL: Activities of daily living; IADL: Instrumental activities of daily living.

Table 2. IADL of People With Chronic Disease Under Study

IADL	Cannot Do, n (%)	Needs Help, n (%)	Independent, n (%)
1. Using the phone	147 (37.2%)	98 (24.8%)	150 (38%)
2. Or using public transportation	243 (62%)	117 (29.8%)	32 (8.2%)
3. Shopping	250 (63.3%)	116 (29.4%)	29 (7.3%)
4. Cooking	288 (72.9%)	77 (19.5%)	30 (7.6%)
5. Doing laundry driving	282 (71.6%)	83 (21.1%)	29 (7.4%)
6. Manage medication	93 (23.5%)	193 (48.9%)	10.9 (27.6%)
7. Doing house work	268 (67.8%)	106 (26.8%)	21 (5.3 %)
8. Handling own finances	176 (44.7%)	74 (18.8%)	144 (36.5%)

Note. IADL: Instrumental activities of daily living.

Table 3. Demographic Data of Participants in the Qualitative Study

Disease	Duration of Care	Duration of Illness	Marital Status	Age	Gender	Participants
ESRD & HTN	2	2	+	50	F	C
ESRD, HTN, & DM	1.5	1.5	-	27		C
ESRD	13	13	+	60	M	C
ESRD & DM	8	15	-	52	M	C
ESRD & DM	8	8	+	37	F	C
Asthma	12	12	+	47	F	C
CVA	10	10	-	30	F	C
ESRD HTN, & CVA	2	2	-	21	F	C
HTN, DM, & MI	1	10	+	60	F	C
MI	2	2	-	30	F	C
CHD	.5	.5	+	50	M	C
CHD	.5	.5	+	25	F	C
MI	2	2	-	25	M	C
DM	25	25	+	58	M	C
CVA & HTN	5	5	-	28	F	C
DM	3	3	+	41	F	C
DM, HTN, & CVA	12	12	+	47	M	C
Asthma	20	20	-	34	F	C
DM, CVA, & HTN	3	3	-	29	M	C
ESRD	8	8	+	62	-	P
ESRD	11	11	+	75	-	P
DM & ESRD	6 m	6 m	+	51	-	P
	20	-	+	47	F	N
	21	-	-	46	F	N
	16	-	+	40	F	N
	27	-	+	51	M	N

Note. *C = Family caregiver; *P = Patient; *N = Nurse; ESRD: End-stage renal disease; HTN: Hypertension; DM: Diabetes mellitus; CVA: Cough variant asthma; MI: Myocardial infection; CHD: Coronary heart disease.

and “transcendental care”. Caregivers with monotheistic cognition and divine protection, along with worship ritual and dynamic presentation were committed to caring for the purpose of the divine rapprochement as the meaning of life. Further, it was indicated that FCGs move toward perfection through this process.

Monotheistic Cognition

Monotheistic cognition was the first category from the concept of “empowering spirituality”, which had four subcategories of “belief in divine power”, “belief in divine wisdom”, “belief in the eternal and everlasting presence of

God”, and “belief of receiving divine grants”.

(a) Believing in the Power of God

Participants believed in God’s ability for the creation and death of humans, doing things beyond human power, and being able to do anything at any moment.

“God does things that nobody can do. For example, a drop of semen can create a person with eyes and ears who can walk (p. 2)”.

(b) Belief in God’s Wisdom

Participants believed in the wisdom of God and mentioned

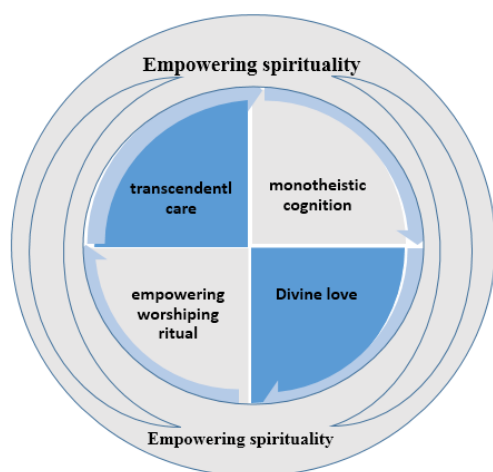


Figure 1. The Dimensions of Empowering Spirituality.

the current status of illness or the task of caring for the patient as a difficult situation (i.e., a divine test). Failure to respond to prayer and orison in maintaining health was also considered as God's wisdom.

"Maybe, it was God's will that this should be the case.

What seems to be evil is accepted when it is God's will (FCG. 17)".

(c) Belief in the Eternal and Everlasting Presence of God

Furthermore, participants believed in the eternal and everlasting existence and presence of God in all places and times.

"Always, there is a God ... who helps us (FCG. 16)".

"I always believe that God is everywhere; God who helps us with our problems (FCG. 16)".

(d) Belief in Receiving Divine Grants

Participants believed that preserving oneself and the family from harm, granting the demands, and obtaining peace were divine blessings. Moreover, FCGs highlighted the capacity for tolerance, the strengthening of will, the improvement of the patient's condition, and the ability to provide proper care from the divine grants. Patients also mentioned the Holy Qur'an as the guideline for their lives. Additionally, they believed that the creation of the whole world for human use is considered as a *divine grant*.

"I believe that God has favored us by letting us bring the patient to the hospital soon because the vessels of the body and heart could be severely damaged due to high pressure (P. 9)".

Based on the operational definition of the "Monotheistic cognition category", participant's experiences indicate that they are also cognitive and believed in the ability of God in the creation and death of a man. In addition, they mentioned that things being done by God are beyond human ability, and believed in eternal existence, eternal and everlasting presence, and the everlasting presence of God as the grace of life in all

places and times, and considered Almighty God as the powerful source of support that they experienced in their life. The current status of a family member with illness was described as divine wisdom. Further, achieving calmness, increasing tolerance, reinforcing wills, having the ability to provide proper care, and improving the condition of the patient and family health from the attention of God were mentioned in this respect.

Divine Love (Agape)

Divine love was the second category from the concept of "empowering spirituality", which has three subcategories including "trust hopefully in God", "lovable patience", "surrender to hearty contentment toward divine fates", and "thankful devotion".

(a) Trust Hopefully

Participants hoped for God's help in difficulty and believed that anyone who wants to move toward God, God will surely not abandon them but will make it easy for them to do difficult things.

"Anyone who wants help from God, God will surely protect him. God does not leave him alone... Success is always with God. Every difficult task is easy with trust in God (P. 17)".

(b) Lovable Patience

Participants believed in the enhancement of care capacity through faith-induced love-based patience to adapt to life-related problems and were pleased with this unbelievable patience for caring.

Caregivers accept care problems with their hearth (e.g., full-time attendance along the patient's low-endurance and early suffering and irritability).

"Despite care problems, we lovely care about our patient..., we try to avoid ungratefulness to Allah during care problems (P. 15)".

(c) Thankful Devotion

Recalling the blessings of God, participants were grateful that the disease could be controlled, and were grateful for the ability to care and the presence of supportive families during illness.

"I am always thankful to God who has given me the patience to take care of my mother (FCG. 7)".

The operational definition of the "divine love" category is that participants hopefully trust in God's support in facilitating hardships and strengthening their ability to care through lovable patience. They were thankfully devoted to God for his support and divine affection as the support to family and to improve the conditions.

Empowering Worshipping Ritual

Divine worship in order to be close to God is the third category derived from the concept of "empowering

spirituality,” which has three subcategories including resorting to *the orison (pray)*, *reciting the Holy Qur’an*, and *praying*.

(a) Orison (Pray)

The first subcategory of the empowering worshiping ritual is to resort God to through prayer. This subcategory consists of praying for patients at their bedside or in private (especially at the onset of illness), their health, release from a bad situation, seek solutions to economic problems, and seek power and pride in care to the patient.

“God helps us save ourselves from this difficult situation. God, I have a problem. I do not know what to do (FCG. 16)”.

(b) Reciting the Holy Qur’an

Participant’s appeal to the Qur’an at the patient’s bedside, participating in group meetings to read the Qur’an, putting this Holy Book above the head of the patient (which makes them calm), solving problems, and strengthening the motivation in taking care of the patient by understanding the meaning of Qur’an.

“I am indebted to Qur’an because this Holy Book gives me peace, especially when I read its meaning (FCG. 18)”.

(c) Prayer

Participants reported their happiness and relief after prayer.

“When my husband was sick, Qur’an and prayer was the only thing that brought peace to me (FCG. 16)”.

The operational definition of the “empowering worshiping ritual” category is that participants are encouraged to receive support in performing their task of caring for a family member with worship, including orison to seek the power, health, strengthening motivation in care by understanding Qur’anic concepts, heart relief with prayer, and communicating with God.

Transcendental Care

“*Transcendental care*” is the fourth category of the concept of “*empowering spirituality*”, which yielded two sub-subcategories of “*committed care*” and “*rapprochement care*”.

(a) Committed Care

The first subcategory of the “*transcendental care*” category is the “*committed care*”, which consists of three subcategories of “*enthusiastic care*, *accurate care*, and *responsible care*”.

(a.1) Enthusiastic Care

Participants, because of their human nature, are interested in goodness and helping other people, especially their family, in full care with the utmost power for achieving health. Caregivers are also interested in informed and voluntary transferring their successful experiences to

other FCGs, especially when they are dealing with difficult situations. Care is a loving expression in addition to being duty and responsibility.

“I’d like to take care of my mother despite the difficulty.

I need to sleep but I have to wake up six to seven times per hour (P. 4)”.

(a.2) Accurate Care

In this study, participants, with their beliefs and acceptance of Imams as their role models in maintaining the patient’s health, were highly motivated and tirelessly adhered to prevent the complications of the disease, care problems, and early death. According to their statements, they precisely follow up care and accompany the patient in performing their duties.

“FCGs are doing the accurate care of the patient based on their belief in Imams as their role models (P. 4, a male nurse with a 27-year history of care for chronic patients)”.

(a.3) Responsible Care

Participants, by adherence to their beliefs and responsibilities, help people with disabilities and the helpless ones. In this way, they provide care for the patient in proportion to their power as financial support, academic education, and practical care.

“Caring for my sick wife is my religious duty and I have to serve her as I did for 25 years (P. 14)”.

“It is cruelty to neglect and leave the patient to suffer. I must seek God’s help and take care of my husband (P. 16)”.

(b) Rapprochement Care (Care-seeking Approach)

The second subcategory of the “*transcendental care*” category is the “*rapprochement care*”, which consists of two sub-subcategories of “*seek divine satisfaction*” and “*excellency care*”.

(b.1) Seek Divine Satisfaction

In this study, caregivers’ intention was to “*seek divine satisfaction*” with the consent of the patient through care as worship. The caregivers hoped to achieve divine satisfaction and felt trust and satisfaction. They provided care with satisfaction.

“We do not claim everything is permitted by God. We only seek God’s satisfaction. Anyway, there is no problem (FCG. 17)”.

(b.2) Excellency Caregiver

Participants expressed dealing with the care problems of patients makes them closer to God. As a result, their close proximity makes them mentally relaxed, satisfied with caring, happy, successful, and excellent in the quality of care services.

“I must endure the difficulty of taking care so that God will satisfy me and facilitate my circumstances. When God is pleased with me, I am pleased and satisfied as

well (P. 3)”.
 “I said to myself, my God, I have no one except you. To express problems with taking care of God, I am more comfortable with God than the doctor or even with my mother. I have received more support from God than family. (P. 16)”.
 The operational definition of the “transcendental care” category indicates that FCGs are devoted to God and fulfill their family and social duties and responsibilities in the care of the family member as financial support, scientific education, and practical care in accordance with their ability. They also follow appropriate care responsibly with calmness and desire with ultimate capacity and accompany patients in carrying out their duties. Participants were surrendered to God through committed care for the sake of proximity and divine satisfaction. This has led to mental relaxation and caring satisfaction, success, and excellence in care and quality care.
 Eventually, in the definition of the operation of the four conceptual categories, “monotheistic cognition”, “divine love”, “empowering worshiping ritual”, and “transcendental care” a more abstract concept emerged that was called “empowering spirituality”. Empowering spirituality in the FCG of a patient with chronic disease is manifested through the acquisition of the cognitive monotheism, along with expressing divine love and practicing religious rituals and caregivers provide care, peace of mind, and satisfaction in addition to efforts for seeking nearness to Allah and care commitment to excellence (Table 4).
Phase 1: Development of Caregiver’s Spiritual Empowering Scale (CSES)

First Draft of the Questionnaire (a Basic Qualitative Content Analysis Study)

In the qualitative content analysis, empowering spirituality was extracted by 187 initial codes, 12 categories including four subcategories, and the operational definition of “empowering spirituality” was extracted as the main theme. Finally, 48 item generations were obtained from data in the qualitative stage.

Review of the International Literature

The 10 items were selected in the related instruments that were applied in Iran, including “spiritual attitude scale”, “functional assessment of chronic illness therapy-spiritual well-being” (FACIT-Sp-12), “religiosity scale and measuring levels of religiosity”, “spiritual well-being scale”.

Pool Item

A pool of 58 items was created at the end of the 1st phase of the study. The research team reviewed the items, after integrating and eliminating the repeated cases, a scale with 17 items (only one of 10 items and 16 of 48 items) entered the psychometric evaluation.

Validity

(a) Face Validity

All the above-mentioned 17 items remained in the face validity. The impact score range was > 1.5 for all items.

(b) Content Validity

Average of the item-level CVIs (S-CVI/Ave) was equal to 0.94. Item “Death and life are always possible by the will of God.” was eliminated (kappa = 69, CVI=0.66). Also,

Table 4. Dimensions the Concept of Empowering Spirituality

Theme	Category	Subcategory	Sub- Subcategory	Code	Quotation
Empowering spirituality	Monotheistic Cognition	• Belief in divine power		- Get the energy of taking care of God - God is the source of mankind’s ability	• It is true that I am old, but God has given me the ability to take care (P. 14). • God bless us. We cannot do anything even breathing without His will (b. 2).
		• Belief in divine wisdom • Belief in everlasting Presence of God • Belief in divine grants			
	Divine love	• Trust hopefully (tavakol) • Lovable patience • Thankful devotion			
		Empowering worshiping ritual	• Orison (pray) • Reciting the Holy Qur’an • Praying		
Transcendental care		• Committed care • Rapprochement care	• Responsible care • Accurate care • Enthusiastic care • Divine satisfaction • Excellency caregiver		

Note. “Empowering spirituality” emerged from four categories in data analysis, including “monotheistic cognition”, “divine love”, “empowering worshiping ritual”, and “transcendental care”.

according research team’s view and panel members’ judgment recommendations two item “I hope for God’s help in the hardships of care” and “I trust to god in the hardships of caring” were integrated in one item “*I hope, God will accompany me in caring*”. Finally, 12 items entered the construct validity stage.

(c) Construct Validity

In exploratory factor analysis, the KMO index was 0.94 indicating the adequacy of data for factor analysis. Further, the Bartlett test of sphericity was significant ($P < 0.001$). Furthermore, principal component analysis via varimax rotation was used and data analysis indicated 12 items (12-60 scores) of CSES loaded on single factor empowering spirituality (Table 5).

Reliability

To assess the stability, the Cranach’s alpha was conducted before assessing the validity of the instrument. First, it was 0.94 and in a good range for 54 participants. All the items of the scale fitted based on the inter-item correlation (LOOP) test $<0.3 >0.7$. In addition, Spearman’s correlation coefficient was 0.57 ($P = 0.000$),

The value of Cronbach’s alpha of the instrument for 395 samples was 0.92. Finally, the standard error measurement was calculated ($SEM = 1.64$) before conducting the ICC test for the test-retest evaluation ($ICC = 0.91$, $CI = 95\%$, $0.90-0.92$), indicating good stability.

Statistical Analysis

Descriptive and inferential statistics were applied for data analysis. The caregivers’ age ($42_{Mean} \pm 12_{SD}$) was in the range of 17-74 years. Moreover, patients aged between 12 and 97 years old ($64_{Mean} \pm 16_{SD}$). Additionally, the

duration of care was reported between 6 months to 30 years. The results further revealed that the majority of caregivers were females (78 %) and married (73.7%). As regard kinship, caregivers were the son (51.8%), wife (21.8%), and bride of the family (10%), and 75% of them lived with a chronic family member. Similarly, 34.7% were taking care of more than 12 hours. The results of the Kolmogorov-Smirnov test showed that spirituality variables are not distributed among the participants. According to the Mann-Whitney test ($P = 0.08$), there was no significant difference between the level of spiritual empowerment among males and females. Further, the relationship between spirituality and age was directly and positively correlated based on the Spearman correlation test ($P = 0.0000$, $r = 0.22$). Furthermore, no significant difference was found between the level of spirituality and job ($P = 0.31$). However, the results of the Kruskal Wallis’s test demonstrated that there was a significant difference between caregivers’ viewpoints about four types of care for patient recovery (care provided by the caregiver, the others, the patient, and the caregiver with Divine support) based on the empowering spirituality level of caregivers ($P=0.035$). Moreover, a significant difference was observed between the provided participatory care (i.e., caregiver, patient, and other people) and care provided by the caregiver with divine support ($P = 0.008$). On the other hand, based on caregivers’ viewpoints, the results of Spearman’s test represented a significant relationship between the “empowering spiritual of the caregivers’ family member” and “believing in God’s will and their effort” as a factor affecting the quality of care ($P = 0.00$).

Discussion

Based on the current data in the first phase and

Table 5. Caregiver’s Spiritual Empowering Scale for People With Chronic Disease

Factor	Item	Rotated Component Matrix	Strongly Disagree (1)	Disagree (2)	Neither Agree nor Disagree (3)	Agree (4)	Strongly Disagree (5)
Empowering spirituality	1. The strength and blessings that God has given me (e.g., health) provides me with ability to take care of the patient.	0.681					
	2. I believe that God is the viewer of my care of the patient.	0.724					
	3. I believe that patient care problems are a divine test for me.	0.532					
	4. God’s support for care is God’s blessing to me.	0.773					
	5. I believe in spiritual rewards in care.	0.733					
	6. Along with trying to care, I desire Divine help.	0.746					
	7. Patience with the hope of God’s help against the problems.	0.741					
	8. I am grateful for the support of God for having the ability to take care of my patient.	0.759					
	9. I take strength and peace in prayer and remembrance of God for my care.	0.733					
	10. I perform the role of caring for my patient as worship with interest.	0.742					
	11. I accept care for Divine satisfaction.	0.710					
	12. Care problems make me closer to God.	0.594					

interpretation of data related to ADL and IADL scales, most individuals with chronic disease are dependent on or in need of help in their daily routine activities. Based on the findings, bathing activities and walking were the lowest independent performance.

Costa Filho et al found that prevalence rates for disability for chronic diseases in at least one IADL and one BADL were 14% (95% CI: 12.9, 15.1) and 14.9% (95% CI: 13.8, 16.1), respectively and the highest prevalence of disability belonged to stroke (30). In another study, Adib-Hajbaghery and Akbari showed that 27% of the elderly needed help in their daily activities (31). Based on the report of Ralph et al, hypertension and myocardial infarction were the most important determinants of disability in women. Diabetes only showed a significant contribution to limitations in BADL. Nationally, 60%-75% of older adults had multiple (2 or more) chronic conditions and the adjusted odds ratio for 3 conditions was 2.2 (a 95% CI of 1.3-3.9) (32).

In this recent study, patients were more dependent on their caregivers regarding walking and bathing. Other studies showed that motor disability is one of the major causes of the inability to live independently in the elderly. Factors such as older age, gender, low literacy, low income, and the combination of multiple chronic diseases increased the dependence on daily activities (31). Hosseini et al indicated that chronic disease can have a negative effect on the basic ADL and 15% of patients were dependent (33). Based on qualitative study data and chronic patients' level of dependence on care, the necessity of designing and implementing a tool for measuring the ability of the caregiver is significant.

Based on the current data in the first phase, the findings of this study showed that the concept of "empowering spirituality" of the FCG in the context of Iran is derived from four categories such as "monotheistic cognition", "divine love", "empowering worshiping ritual", and "transcendental care". Each of these categories has several subcategories. Khorashadizadeh et al classified spiritual well-being in patients based on Islamic teachings into three main components of love, science, and practice (34). Based on the review of the Islamic text definition of spiritual health, three areas were expressed, including insight, tendency, and behavior, the final model was explained by cognitive-emotional and behavioral dimensions (35). The spiritual dimension in family therapy includes cognitive, affective, behavioral, and developmental dimensions (36). According to Islamic literature, spirituality means the use of wisdom, tendencies, and abilities for knowing and worshiping God.

Monotheistic cognition. The cognitive of monotheism was the first category of the concept of *empowering spirituality* which included four subcategories as "belief in divine power, belief in divine wisdom, belief in the eternal and everlasting presence of God, and belief in receiving divine grants". Further, Moeini stated that for some patients, the only way to be relieved during chest pain is to

hope in divine power (37). Faith in the divine wisdom was another category of the cognitive indicators of spiritual well-being (20). In the study of Brabadi, healthy participants thought of God as the innate wisdom who makes challenges to test His servants (38). Participants expressed the eternal presence of God in a supportive presence and grace of life. In another study, Berabadi reported that most healthy subjects considered God as helping, accessible and responsive, as well as intimate and close (38). Similar to "monotheistic cognition", in a recent study, Alavimajd et al proposed "belief in God" as one of the themes of spiritual well-being and the source of energy for life (39).

Divine love. It was the second category from the concept of "empowering spirituality", which had three subcategories including "trust hopefully in God", "lovable patience", and "thankful devotion". Love is a positive heart orientation that establishes the basis of human relationships in social life, and the relationship between creature and creator (40). In the study by Ebrahimi Belil et al, reliance on God, patience, and thankfulness were the main aspects of spirituality among patients with chronic illnesses. Trust in God's will and believe in His help and support for those who obey Him. People with firm religious beliefs confide in God and hopefully continue their lives even in the absence of effective support systems (41). Moreover, patience against the problems and thanks to God are issued from interest and love to God (42). Additionally, safe attachment to God can be a positive and significant predictor of patience (43). Zamanzadeh et al showed that spiritual care is an effective relationship with patients that carries love, trust, and happiness (44). Similarly, gratitude is considered as an emotional sign in committed religious people. The results of the study by Al-Seheel and Noor demonstrated that thanksgiving and appreciation increase happiness and satisfaction in life (45). In addition, Ajam Zibad et al concluded that tolerance, trust, attention to God's satisfaction at any time and God's remembrance are listed as the indicators of the functional spiritual wellbeing. Further, submission to God and the sense of God's satisfaction were categorized as the emotional indicators of spiritual well-being (20). From Motahhari's point of view, the heart, verbal, and practical appreciations are considered as gratitude levels. It seems that the differences in data property classes lie at these three levels (46).

Empowering worshiping ritual. This was the third category of the concept of "empowering spirituality". It included three subcategories encompassing resorting to the "orison, reading Qur'an, and praying". Worship is a connection between the devotee and God (47). Ghobary Bonab et al showed that Muslim patients believe in prayer and remembering Allah by which they increase their tolerance and patience and decrease their loneliness (16). In another study, Yadak et al represented that reading, recitation, and listening to Holy Qur'an has been a way of healing and treatment in the studied patients during the

last 12 months (48). Furthermore, Van Rooyen et al stated that prayer and recitation of the Qur'an have a direct relationship with self-esteem, regulation of emotional states, and normal social behaviors. In other words, using prayer and religious practices is an effective everyday way of coping with stress (49). Moreover, Surbone and Baider declared that many cancer patients rely on religious beliefs as a power and hope source and can cope with their fear and loneliness during their illness (50). More precisely, seeking proximity to Allah is the ultimate goal of the rituals and practices of Muslim people.

Transcendental care. This is the fourth sub-subcategory of the concept of “*empowering spirituality*”, which consisted of two sub-subcategories of “*committed care*” and “*rapprochement care*”. Based on the report by Zamanzadeh et al, nurses experienced spiritual excellence during their care and understood closeness to God (44). The first subcategory of “*transcendental care*” was the “*committed care*”, which encompassed three subcategories of “*enthusiastic care, accurate care*” and “*responsible care*”. According to Atashzadeh Shoorideh et al, feeling the responsibility is a sense of commitment that nurses are bound to answer for care responsibilities. Thus, the actions taken must be accurate, timely, and full of kindness (51). In the study by Jalali et al, commitment to care was a sub-concept of care conscience (52). Additionally, Mahmudi Shen et al reported that the nature of nursing is such that a person must be affectionate and sympathetic and sympathize with the patient (53). The findings of Atashzadeh Shoorideh et al showed that targeted care in order to regulate care, correct care, and reporting are among the responsibilities of FCGs (51). Based on the results of Shafipour, from the perspective of cardiac patients, the nurse's commitment was described from the concepts of responsibility and human relationships among nurses (54).

The second subcategory of “*transcendental care*” was “*rapprochement care*”, which had two sub-subcategories of “*seek divine satisfaction*” and “*excellency caregiver*”. In the study by Ebrahimi Belil, people with chronic diseases worshiped God for the sake of God's satisfaction (41). The nurses sought spiritual transcendental and God's satisfaction in the satisfaction of the people (44). All participants stated that the ultimate goal of worship is to feel intimacy and closeness to God and to achieve inner comfort (i.e., a sense of happiness). The findings of Atkinson showed that the individual's commitment increases when a job is considered as a pathway (55). In this regard, Sadat Hosseini reported that nurses try to achieve spiritual excellence during the nursing process (23). The belief of FCGs in God's protection as the source of their ability to cope with threatening conditions of care is important. Based on the findings of studies, spirituality is a very strong coping strategy and spirituality/religiosity has helped them to have an optimistic view of events (11,18).

The empowerment of FCG is defined as “positively controlling one's mind and body, supporting the independence of the care receiver, and creating constructive relationships with other people around them” (56). Some studies reported knowledge, support, competence, and self-efficacy in several respects as the dimensions of FCGs' empowerment (57). In addition, Spirituality is defined as energy, meaning, purpose, and awareness in life, which lead to the strengthened power for coping with problems. Further, it is considered as an attempt to achieve holistic humanity (58). Despite the difference in the concept and ways of achieving spirituality in different cultures, its dimensions are somewhat the same as a true concept in various studies.

The CSES is a reliable and valid instrument that measures spirituality in the caregivers' of people with chronic diseases. In the study by Jafari et al, spirituality was assessed with the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scale (FACIT-Sp) with 12 items. The Persian version of the FACIT-Sp scale is a reliable and valid tool for the clinical assessment of the spiritual well-being of Iranian Muslim and Farsi-speaking patients in other regions of the world who are receiving treatment for cancer. Cronbach's α reliability coefficient for the FACIT-Sp subscales ranged from 0.72 to 0.90. The CFA generally replicated the original conceptualization of the three subscales of the FACIT-Sp12 (i.e., peace, meaning, and faith) (59). Concurrently, in the present study, the category of “*monotheistic cognition*” and the subcategory of the “*rapprochement care*”, which contained two sub-subcategories of “*seek divine satisfaction*” and “*excellency caregiver*” led to the growth of the perfection of personality in the caregiver.

Pinto and Pais-Ribeiro Spirituality Scale (PP-RSS), which was applied in the study by Pinto and Pais-Ribeiro (2007), is an instrument consisting of 5 items centered on two vertical and horizontal dimensions. The vertical dimension is associated with the same belief regarding the cognitive divine of CSES in this study and the horizontal dimension is related to hope/optimism as the subcategory trust hopefully (tavakol) of CSES in this study. Similar to the current study, the spirituality score was reported in the above-mentioned study, indicating a high spirituality level. The internal consistency of the PP-RSS scale was equal to the validity of the study and considered acceptable ($\alpha = 0.64$). Furthermore, a positive and statistically significant correlation as found between HHS and the overall score ($r = 0.605$) of PP-RSS ($P < 0.01$).

Moreover, there was a relationship between the level of hope and spirituality thus, important positive factors could be considered for the elderly caregivers in the face of the care activity. Additionally, an association was observed between hope and spirituality in patients undergoing hemodialysis (11). Coban reported that the Spiritual Care-Giving Scale was timely and accurate for determining participants' knowledge, attitudes, and beliefs about

spiritual care. These five factors were “general properties of spiritual care”, “spirituality perspectives”, “defining spiritual care”, “spiritual care practices”, and “spiritual care attitudes” among which, spirituality perspectives, spiritual care practices, and spiritual care attitudes supported some dimensions of CSES in this study. In addition, the split-half reliability of SCGS was 0.88 (13).

Among the four subscales of the Spiritual Support Scale (i.e., emotional/informational, tangible, the combined affectionate and positive social interaction, and spiritual subscales), emotional and tangible dimensions supported some dimensions of CSES in the present study.

Conclusions

People with chronic diseases are dependent on other people or need help in their activity daily living. Ultimately, FCGs believe in the eternal attention of the wise and almighty Allah as a powerful supporter in difficult situations. In addition, they are thankful for the received support, which has had significant effects on their ability for care. Further, FCGs try to be satisfied and be near to God by increasing their capacity through presenting worship rituals and committed care to a family member with chronic disease.

The clarification of *empowering spirituality* concept and identification of its sub-concepts provide the basis for assessing the spirituality empowerment in FCGs in order to increase the efficiency of the power and spirituality of the family in the care of people with chronic illness. It seems that a better understanding of *empowering spirituality* can provide a framework for planning and applying comprehensive training for the spiritual empowerment of FCGs. This is possible by emphasizing the importance of the spiritual empowerment approach as a low-cost, low-risk, and effective approach for improving the quality of care and explaining the concept of *empowering spirituality* in FCGs for caring for people with chronic disease. Moreover, it strengthens the strategies of *empowering spirituality* by FCGs for the continuous improvement of quality care. Ultimately, the findings of this study contribute to different areas of education, research, policy, clinics, and the development of nursing knowledge and practice. Additionally, the current study provides early evidence for the validity and reliability of the CSES in the informal caregivers of patients with chronic disease. Additional testing in other populations is recommended in this regard. Applying CSES for informal caregivers could aid health providers in the identification of spiritual empowerment, enabling them to develop the plans for individualized and high-quality care.

Limitations

Limitations such as long times required for objectivizing the concepts are significant because of the complexity of spirituality concept. Participants in the study often spoke in local accents and were Shiite. In addition, the text of the interviews was first translated and then edited in Persian

and finally in native English. Another shortcoming of this study is that the interviews were occasionally interrupted due to limitations in time and location.

Conflict of Interests

Authors have no conflict of interests.

Ethical Issues

The current study was approved by the Ethics Committee for Medical Research, Tarbiat Modares University, Tehran, Iran (Approval No. IR.TMU.REC.1395.330). The purposes of this study were clarified for all participants, and their oral consent was taken for participation in the study. Further, they were allowed to withdraw from the study at the desired time without any risk for delivered services.

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