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# Development and psychometric evaluation of the perceived care tension questionnaire for caregivers of hemodialysis patients: A mixed method study

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## Abstract:

**BACKGROUND :** The complex, multifaceted care environment and the threatening situation of caring for hemodialysis patients cause tension in their family caregivers. Due to the severe tension, family caregivers are likely to ignore their basic needs and only pay attention to the patient's needs and related issues. This study was conducted with the aim of designing and evaluating the Perceived Care tension Questionnaire for Caregivers of Hemodialysis Patients (PCTQHFC).

**MATERIALS AND METHODS:** The present study was a sequential exploratory mixed methods study of scale development variant conducted in two phases: qualitative and quantitative. This study was conducted in 2019 in Shahrekord. The qualitative phase included item development and scale development. In the quantitative phase (Item Analysis), the validation characteristics of the tool were examined using face, content and construct validity, and its reliability by internal consistency and stability. Findings were performed using software SPSS 18.

**RESULTS:** Principal components analysis with orthogonal rotation to generate factors, showed that five factors, namely emotional exhaustion, inadequate social support, care burden, confusion and ambiguity and lack of adaptability skills had an eigenvalue of higher than 1, so that they explained, respectively, 75.98%, 61.36%, 72.49%, 76.33%, and 70.31% of the total variance. The internal consistency was obtained 0.811 and the inter-class correlation coefficient for the whole instrument 0.832.

**CONCLUSION:** PCTQHFC is a culturally appropriate measure with strong psychometric properties. The instrument designed in this study measures the care tension of hemodialysis patients. Therefore, researchers, health-care providers, and community health policymakers can plan and implement interventions to reduce the tension of caregivers of hemodialysis patients by analyzing and identifying the tensions of caregivers.

## Keywords:

Caregivers, hemodialysis patients, Iran, perceived care tension questionnaire, psychometrics

## Introduction

The growing prevalence of chronic diseases, the increasing number of hospitalizations due to these diseases, and the high cost of health care services have posed a significant challenge to

care systems.<sup>[1]</sup> Among chronic diseases, chronic kidney disease (CKD) is one of the leading causes of mortality and disability worldwide.<sup>[2,3]</sup> CKD refers to the progressive and irreversible reduction of the kidney, so that the kidney is unable to maintain the internal environment of the body. When kidney function reaches only 10%,

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the end-stage renal disease is developed, which can be threatening and dangerous if left untreated.<sup>[4]</sup> The prevalence of CKD is increasing not only in Western societies but also in developing countries.<sup>[5]</sup> More than one and a half million people in the world live on hemodialysis or peritoneal dialysis and kidney transplantation, which is expected to double in the next decade.<sup>[6,7]</sup> In total, on average, one out of 10 people in all societies have a kidney disease and \$ 110 billion a year is spent on kidney failure across the world.<sup>[8]</sup> Today, most family members are responsible for caring for the patient.<sup>[9]</sup> Caregivers include spouses, children, siblings, friends, or other family members who assist these patients at different stages of the disease, and this care is not delivered only in the advanced stages of the disease.<sup>[5]</sup> This care can entail physical, psychological, psychological, and emotional dimensions.<sup>[10]</sup>

Living with chronic disease patients can be stressful, limiting, and stressful for both the patient and their caregivers.<sup>[10,11]</sup> Therefore, it is important to support family caregivers and identify their needs to provide quality care to patients with chronic diseases.<sup>[12]</sup> Compared to the caregivers of other chronic diseases patients, caregivers of hemodialysis patients face different issues and problems, such as frequent hospitalizations and the use of various medications by the patient. In addition, these caregivers often spend much time caring for these patients and endure a lot of fatigue and care tension, which increases their stress. In general, family caregivers of hemodialysis patients report high levels of stress, high care burden, depressive symptoms, and reduced physical and emotional health.<sup>[13]</sup> Caregivers prefer the needs of patients to their own needs, and ultimately take less time to carry out activities that promote their health, which can have adverse effects on their health and quality of life.<sup>[14]</sup> Because caregivers usually take on the heavy responsibility of delivering care while they have not already received the necessary preparation and guidance to do so, many problems and challenges will be created for them.<sup>[14]</sup> Many factors such as an acute illness and unhealthy or hospitalization of a member of the hospital can lead the family to tension and turmoil<sup>[15]</sup> and as a stressful event lead the family to crisis.<sup>[16]</sup> Often, seeing a loved one in a threatening situation and a stressful care environment is one of the factors that increase the concerns of family caregivers. In such cases, due to severe anxiety, family caregivers are likely to ignore their basic needs and only pay attention to the patient's needs and related issues.<sup>[17]</sup>

Today, efforts are being made to increase the efficiency and effectiveness of care provided by caregivers by identifying and explaining the care tensions of family caregivers of patients. Given the importance, discovery and explanation of the challenges and

tensions in caregivers of hemodialysis patients in caring for these patients, and because no integrated and community-based tools have yet been designed to assess care tension among family caregivers of hemodialysis patients in the world, this study was conducted with the aim of designing and evaluating the Perceived Care Tension Questionnaire for Caregivers of Hemodialysis Patients (PCTQHFC).

## Materials and Methods

### Study Design and setting

This study was a qualitative-quantitative study of sequential exploratory mixed methods design of instrument development variant. Exploratory design is a type of mixed methods design, and its primary purpose is to generalize data from a few individuals to a larger sample.<sup>[18]</sup>

### Participants and sampling

Relevant literature, hemodialysis patient caregivers, and faculty members were samples of this study in qualitative and quantitative phases. Purposeful sampling was performed in the qualitative phase and convenience sampling in the quantitative phase.

Family caregivers whose patients were under hemodialysis and definitive diagnosis of CKD had been recorded by a nephrologist in their medical records were considered eligible to be enrolled in the study.

### Inclusion criteria for hemodialysis patients

Providing consent to participate in the study; being the main caregiver of the patient. Being a family member of the hemodialysis patient; and lack of suffering from mental and cognitive diseases. Exclusion criterion: Lack of volunteering to participate in the study.

### Procedures

In this study, the design and validation of the questionnaire were performed based on the proposed steps of Schwab. Schwab divides tool design and psychometry into three main stages, including item development, scale development, and evaluation scale.<sup>[19]</sup> In the present study, the first and second stages are qualitative and the third stage is quantitative:

### Qualitative phase

This step is the first step in tool development and involves developing unique items.<sup>[20]</sup> Item development is the most important part of the design of precise instruments, for which the use of two inductive and deductive approaches is recommended.<sup>[21]</sup>

In this study, two deductive and inductive approaches were used to develop the items:

By reviewing the texts, the researcher gained access to a variety of potential items that could accurately and meaningfully evaluate the construct as much as possible. In the present study, library and electronic resources were searched for the tools or scales on care tension.

Inclusion criteria were original articles and dissertations in Persian and English.

Search for content related to this area was done without time constraints and using keywords Questionnaire, Instrument Tool, caring tension, and family caregiver in databases such as SCIEDIRECT, OVID, Google, and Google Scholar.

The setting of this study is the city of Shahrekord, which is one of the western regions of Iran. What makes the city suitable for this study was the researchers' access to samples with maximum cultural variation and other confounding variables in the care tension of hemodialysis patients. The study setting was selected at the participant's convenience. Data were collected using individual and face-to-face interviews with 21 hemodialysis patients. Interviews lasted for 20–60 (average: 45) min. Interviews were recorded with the permission of the participants, and then transcribed word for word. Interview questions were raised with the help of an interview guide [Table 1].

Before the start of each interview, participants were provided with a letter of consent containing explanations about the purpose of the study, a thorough introduction of the researcher, an explanation of the study procedure, sampling, and the benefits and harms of the study, and then they were asked to sign it or verbally declare their volunteering to participate in the interview if they wished to do so. Furthermore, before each interview, the demographic characteristics checklist was completed by all participants and then the interview was started by establishing a communication with and gaining the trust of the partners, during which the participant was asked to talk of their perceptions and experiences about the stressful factors of care. At the completion of each interview, the participants were asked to speak about issues and points that had remained unspoken, and then the interviewer told them that additional interviews would be likely. In this study, the data collection process continued until data saturation was achieved; that is,

no new data could be drawn from the statements of the participants, all the codes and categories had been completed, there was no information that required a new code or the development of existing codes, and in-depth and rich data had been obtained about the phenomenon under study.

Methods of collecting information at this stage included semi-structured interviews and field note-taking.

Data rigor was assessed based on four criteria: credibility, dependability, confirmability, and transferability.<sup>[22]</sup> In this study, to ensure credibility, efforts were made to select participants by maximum variation sampling (age, gender, marital status, occupation, education level, length of patient care, care hours, etc.). The transcripts of the interview and the drawn codes were presented to a number of participants so that they could comment on their accuracy (member checking). For confirmability, an attempt was made to provide a complete description of the research process, including data collection, analysis and formation of themesto allow auditing the research by the audience and readers. In order to facilitate transferability, the researcher made attempts to enable the reader to judge the applicability of the findings in similar situations by clearly describing the context, selection and characteristics of the participants, data collection, and analysis process.

Attempts were also made to increase transferability by providing rich and accurate findings with appropriate citations.

At this stage, three important steps in tool design were taken:

1. At this stage, the items were combined to form a questionnaire<sup>[23]</sup>
2. Researchers paid attention to the adequacy of the number of items. Gillham describes the items draft and layout as two important key points that should be taken into account in designing a questionnaire. Categorizing and organizing items (in a particular order) can make it easier for respondents to respond to them.<sup>[24]</sup>

In this study, researchers thought about how to order items and whether they could integrate one item into another

**Table 1: Some examples of questions are as follows**

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Please talk about your experience of caring for your patient  
 What issues and problems do you face in caring for your patient?  
 What makes you feel better as a family caregiver?  
 What makes your situation worse as a family caregiver?  
 If you could change something to take better care of your patient, what would you change?  
 The interview continued with questions such as Do you need anything else to talk of?

---

3. The response format of the items was also determined, which was in the form of a Likert scale (I'm pretty sure, I'm almost sure, I'm a little sure and I'm not sure). The choice I'm pretty sure was scored 4 and the choice I'm not sure was scored 1.

In the social sciences, the Likert scale is the most common scale used in designing attitude scales.<sup>[25]</sup>

### Quantitative phase

This step included performing the psychometric procedures of the designed questionnaire's validity (face, content, and construct) and reliability and introducing the characteristics of the participants and how to collect and analyze quantitative data:

Face validity was investigated in both qualitative and quantitative phases. From a qualitative perspective, the face validity of a tool refers to the relevance of its appearance to what it is to measure, from quantitative perspective, face validity is calculated by the formula below:

$$\text{Importance (\%)} \times \text{Frequency} = \text{Impact score}$$

Items with an impact score of equal to or >1.5 were remained and other items were deleted.<sup>[26]</sup> In this study, to determine the qualitative face validity, 10 hemodialysis patients were asked to comment on the level of difficulty, appropriateness, ambiguity and complexity of each item, and quantitative face validity was investigated by measuring the impact score according to the same individuals' comments on the importance of each of the items.

Lynn considers content validation as an accurate assessment that is fundamental to all basic tools.<sup>[27]</sup> In fact, at this stage, quantification-judgment was performed, which involved asking a number of experts to evaluate the items individually as well as to evaluate the whole instrument.<sup>[28]</sup> In this study, both qualitative and quantitative methods were used to investigate content validity. In the qualitative method, the observance of the grammar, the use of appropriate words, the placement of the items in their proper place and the appropriate scoring were examined by the experts. To quantitatively validate content validity, Content Validity Ratio (CVR) and Content Validity Index (CVI) were measured.

Criterion validity was not met because no external standard was found for the instrument being made.

Lawshe provided a model for determining content validity in which the questionnaire is provided to a panel of experts and they comment on the necessity of the questionnaire items.<sup>[29]</sup> In this study,

the questionnaire was E-mailed to 10 faculty members who had quality work experience and experience in instrument development and were asked to assess the questionnaire in a three-point scale (Not Essential, Useful but not Essential; Essential). The results were compared with the criteria in the Lawshe's table. The CVI is the ratio of experts' agreement on the relevance of each item, that is, the number of experts who gave scores of 3 and 4 to each item is divided by the total number of experts, which represents the ratio of the agreement on the relevance of each item.<sup>[30]</sup> In this study, a questionnaire was sent via E-mail to 10 experts (the same people who were invited to examine the face validity and determine the CVI), to rate the items on a 4-point Likert scale (from Irrelevant to Absolutely relevant).

Factor analysis is the most common analytical technique for reducing data and modifying constructs. If the work is done well, all the dimensions of a dimension must be related to each other and only to a single factor.<sup>[31]</sup>

In this study, construct validation was done by exploratory factor analysis. In exploratory factor analysis, the researcher has no particular expectations about the number or nature of the underlying constructs or factors. Principal components analysis with orthogonal rotation is the most common method for factoring in studies. Before the extraction of factors, to ensure that the items are appropriate for principal components analysis, the Kaiser-Meyer-Olkin and Bartlett's test of sphericity were performed to investigate sufficiency of sampling. Bartlett's test of sphericity was also used to investigate whether the correlation matrix obtained was significantly different from zero and based on which a factor analysis could be justified? Or was there adequate correlation between the items of the questionnaire to integrate them.<sup>[32]</sup> In the present study, interclass correlation coefficient and stability were used to evaluate the reliability:

The most common way to evaluate interclass correlation is to measure Cronbach's alpha, which provides an indicator of the mean correlation between all the items that make up the tool. Regarding this, Silber *et al.* recommends calculating mean correlation item-inter.<sup>[33]</sup>

Test-retest is used to assess the stability of a scale by administering the same instrument to the same people in two different situations.<sup>[34]</sup> In this study, to determine the stability of the questionnaire, 15 caregivers of hemodialysis patients were asked to fill out the final version of the questionnaire twice with a 2-week interval, and then the interclass correlation coefficient was calculated for all dimensions as well as for the entire questionnaire. ICC is a type of reliability and a form of alpha coefficient that simultaneously represents both

a measure of the agreement between individuals and a measure of reliability in terms of the average rank of individuals.<sup>[33]</sup>

In most cases, the format of the item determines the overall scoring procedure. If the answer format is a Likert scale, the total (aggregate) score for the instrument is usually calculated by summing the value of the items.<sup>[35]</sup> In the present study, the total score was calculated by summing the answers to each item that was rated on a 7-point Likert scale. The minimum and maximum possible scores on the questionnaire are 52 and 364, respectively. A higher score indicates higher care tension perceived by caregivers of hemodialysis patients.

### Data analysis

In the qualitative section, after the interviews, the data were analyzed by the conventional content analysis. Qualitative content analysis was performed in three steps, namely preparation, organization and reporting. The first step began with the selection of the unit of analysis.<sup>[36]</sup> The most appropriate unit of analysis, according to Graneheim and Lundman, is the entire transcript of the interview.<sup>[37]</sup> The second step entailed open coding and the creation of categories, and the third step entailed the presentation of a concept map, a model or a representation of the categories.<sup>[38]</sup> In this study, to analyze the data, first the audio file of the interviews was transcribed, and then with a careful study of the transcripts that formed the units of analysis, the researcher tried to achieve a general sense of them. The transcript of the interviews was then organized with open coding. The drawn codes were managed manually. Frequent study of the drawn codes helped to identify similarities and differences between them and to classify them. Eventually, as the analysis process progressed, connections between specific categories and then hidden themes in the text of the interviews were extracted. In the quantitative section, after completing the questionnaires, the data were analyzed using SPSS18 software ((SPSS Inc, Chicago, Illinois)). The absolute and relative frequency of quantitative and qualitative variables under study were calculated. Spearman's correlation coefficient was used to investigate the relationship between factors. Cronbach's alpha values range from zero (no stability) to 1 (complete stability). For alpha, a minimum level of 0.7 was considered,<sup>[39]</sup> and for the mean correlation within the items, values between 0.10 and 0.50 were accentuable.<sup>[40]</sup> The significance level in this study was  $P < 0.001$ . To calculate the CVR, Lawshe's table with a minimum acceptance of 0.62 was used.<sup>[41]</sup> The minimum acceptable value for Kaiser-Meyer-Olkin (KMO) was 0.6.<sup>[42]</sup> In this study, Eigenvalues higher than 1 were the criterion for retaining factors. For exploratory factor analysis, 300 samples were invited to cooperate and the appropriate factor load was considered to be at least 0.4.<sup>[23]</sup>

In this study, ethical considerations were fully considered so that the ethics committee of Shahrekord University of Medical Sciences approval the study protocol (ethics code: IR. SKUMS. REC.1398.212), and a letter of introduction was also obtained from the responsible authorities. Besides that, the informed oral or written consent to participate in the study was obtained from the participants after explaining study objectives, the procedures of cooperation with the researchers and data collection to them. Moreover, data recording in the qualitative phase, the role of the researcher and the participants, and the observance of the privacy of the people were carefully accomplished with the necessary and ethical arrangements. Determining the time of the interviews at convenience of the participants, reserving the right of the participants to withdraw from the study whenever they wished, and keeping all information confidential (including the names of the participants, questionnaires, interview files and transcripts) in both quantitative and qualitative phases were fully taken into account.

### Participants characteristics

Of our participants, 53.4% were male, 65.5% were single and their average age was 47.9 ( $\pm 9.5$ ) years [Table 2].

The mean ( $\pm$ standard deviation) age of our participants was 42.13 ( $\pm 5.22$ ) years. 59% of the samples were male and 58.5% were married. Regarding occupation, 48% of caregivers were employed, and the rest were housewives (23.5%), unemployed (25%), and students (3.5%).

The mean ( $\pm$ standard deviation) duration of chronic renal failure in patients was 31.6 ( $\pm 0.71$ ) months. Most caregivers cared for their patients for an average of 7.5 h a day.

### Item development

A total of 22 publications related to the studied subject were retrieved and 26 items were designed by reviewing them. From the analysis of the qualitative phase of the study, 50 items were drawn [Table 3].

### Scale development

At this stage, the researchers examined and reviewed the items. Three items were deleted due to duplication and 2 items were merged. Finally, 71 items remained.

### Item analysis

#### Face and content validity

In the study of face validity, 7 items were deleted due to receiving a score of  $< 1.5$ .

In the qualitative study of content validity, no item was deleted; however, 11 items were revised and all the

**Table 2: Demographic characteristics of study participants (n=300)**

Variable	Grouping	Frequency, n (%)
Gender	Male	110 (36.7)
	Female	190 (63.3)
Sufficiency of family income	Insufficient	102 (34)
	Medium	108 (36)
	Higher than medium	80 (26)
	Much higher than medium	10 (4)
Being able to do personal activities	Very highly able	10 (4)
	Highly able	72 (24)
	A little able	127 (42)
	Seldom able	91 (30)
Patient's level of care-related dependence	Very much	98 (33)
	Much	104 (35)
	Little	79 (26)
	Very little	19 (6)

**Table 3: Examples of the process of codifying the items of perceived care tension questionnaire in caregivers of hemodialysis patients**

Construct	Item	Participants' viewpoints and experiences
Emotional exhaustion	Lack of spirit and extreme fatigue due to patient's numerous problems	We are involved in his problems and troubles that we've got tired and nervous. This makes my sister and I suffer a lot, and no other spirit and stamina have been left for us
Care burden	Caregiver's continuous engagement with care process	Everyone has time every 7 days of the week, but with dialysis we have three days and I am always sick and I can't do the rest
Inadequate social support	Caregiver's drawing attention to receive support and talking of failure	I have frequently faced many questions and ambiguities about my patient's problems at home, and there has been no one or institution to support me
Confusion and ambiguity	Caregiver's worrying about the occurrence of an unwanted event as a result of neglect	Most of the time, when my patient is asleep, I pick up a mirror and hold it in front of his mouth to make sure he is breathing, or when I cook, I spread my patient's bed next to the kitchen entrance. I'm very scared of what may happen to him and I won't notice
Lack of adaptation skills	Caregiver's need for better understanding to solve problems and adapt to the situation	Many times, I thought about a problem for a few days and it took us a long time to figure out where the problem was so I could solve it

proposed changes were made to the appearance of the items. In the calculation of CVR, 4 items were deleted and in the study of CVI, 3 items were deleted. Finally, 57 items remained in this stage.

### Exploratory factor analysis

Finally, a 57-item questionnaire was prepared for the exploratory content analysis. KMO and Bartlett's test of sphericity were performed before the exploratory factor analysis. In this study, the KMO value was 0.838. Bartlett's test of sphericity was also significant ( $P = 0.001$ ;  $\chi^2 = 2843.3$ ). Factor analysis of the main component showed that the five factors had eigenvalues  $>1$  [Figure 1], which explains 75.98%, 61.36%, 72.49%, 76.33% and 70.31% of the total variance, respectively. In this stage, 5 items were deleted due to factor loading of  $<0.4$ , and finally 52 items with factor loading of 0.562–0.882 in the five-factor model, namely, emotional exhaustion, inadequate social support, care burden, confusion, and lack of adaptation skills remained [Table 4 and Figures 1, 2].

### Reliability

In this study, to determine the internal consistency between items in a sample of 300 hemodialysis patients, Cronbach's alpha coefficient was calculated at 0.811. No items were deleted at this stage. In order to determine the stability of the questionnaire in terms of repeatability, the interclass correlation coefficient was calculated for all dimensions, which was 0.832 for the entire instrument [Table 5].

In the present study, Spearman's correlation coefficient was used to describe the linear relationships between the factors and the results showed that there was a strong and positive correlation between the main factors ( $r = 0.603, 0.923$ , respectively,  $n = 300$ ,  $P < 0.0001$ ) [Table 6].

### Discussion

Chronic illness in a family member affects the whole family, and the resulting economic, psychological, and social problems change their lifestyle and create daunting

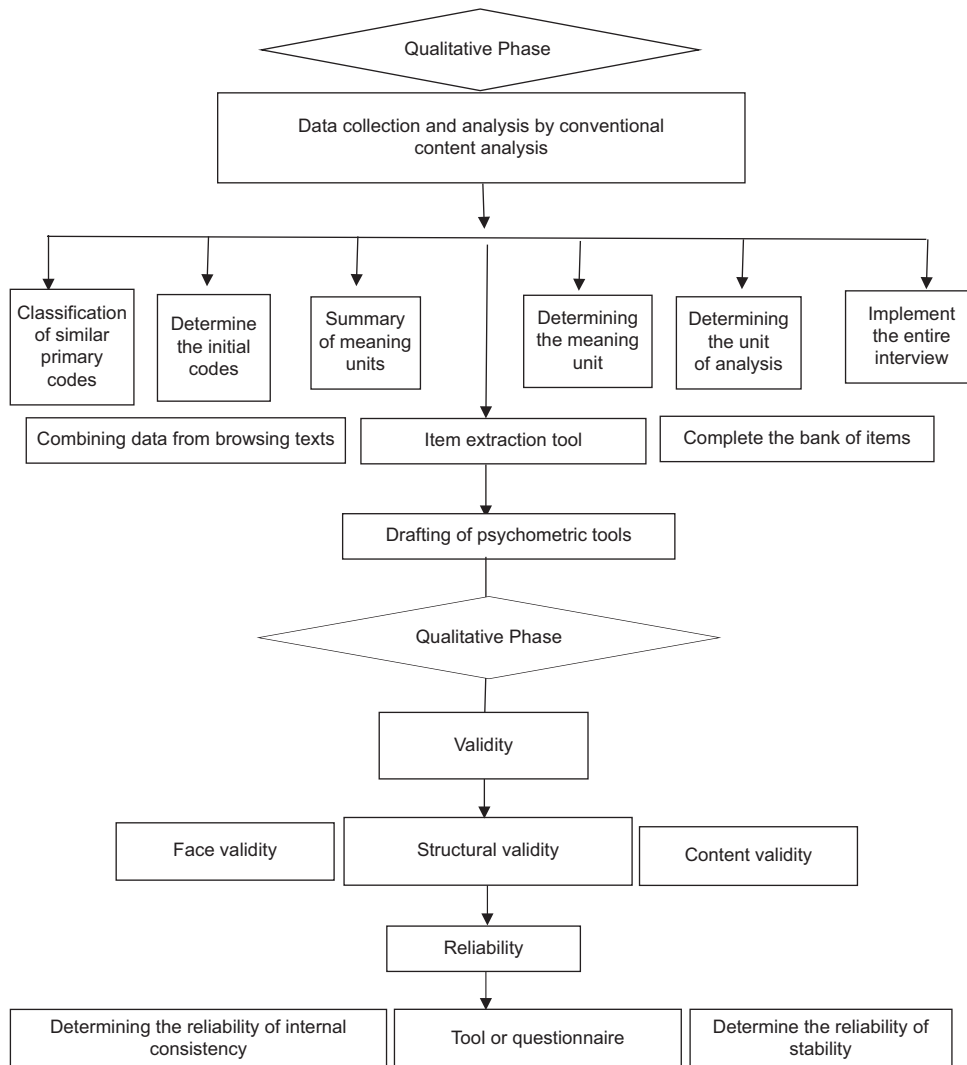


Figure 1: Flow chart of the study design

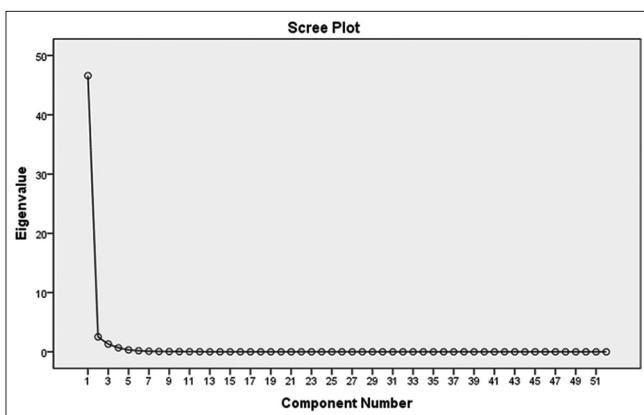


Figure 2: Scree plot of perceived care tension questionnaire for caregivers of hemodialysis patients

These caregivers often experience impairment in awareness and skills related to patient care, lack of assistance from health-care providers, lack of social support, additional stress related to disease progression, incapacity after illness, and increasing complex care needs.<sup>[46,47]</sup>

Over time, as the patient’s condition worsens, care tension increases, which in addition to the physical and mental problems for caregivers, will have consequences such as family isolation, disruption of family relationships, inadequate patient care, and ultimately abandonment of the patient. Therefore, these caregivers are referred to as predisposed to disease or hidden patients.<sup>[48]</sup>

challenges for family caregivers, so that, in addition to physical stress, caregivers experience various emotional stresses such as depression, anxiety, anger, frustration, hopelessness, and feelings of shame and guilt.<sup>[43-45]</sup>

A study conducted by Belasco *et al.* found that 70% of caregivers had two major problems, namely, problems with patient care and treatment and problems with adaptation to their own caring responsibilities. Therefore, in addition to caring skills, caregivers need to use skills

**Table 4: Table of factors after varimax rotation in perceived care tension questionnaire for caregivers of hemodialysis patients (HFCPCTQ)**

Dimension	Item	1	2	3	4	5
Emotional exhaustion	Constantly watching my patient's condition makes me sad	0.844				
	Continuously doing the tasks of a patient care has become tedious for me	0.641				
	My mind is always engaged with my patient's illness	0.743				
	I experience overwhelming stress in caring for my patient	0.718				
	I feel tired and frustrated as I have to go to the hospital so many times	0.866				
	I feel guilty that taking care of my patient prevents me from paying attention to the affairs of other members of my family	0.623				
	I feel guilty when my patient's condition worsens	0.701				
	The patient's frustration with his illness leads to mental fatigue in me	0.562				
Care burden	I have financial concerns about medicine, dialysis, and living expenses		0.871			
	Taking care of my patient has overshadowed my life		0.742			
	Taking care of my patient has made me give up my fun and work		0.697			
	Taking care of my patient has led to improper handling of other family members		0.856			
	Taking care of my patient and multiple tasks has caused me a lot of stress and fatigue		0.784			
	Due to the multiplicity of tasks, I have a conflict in deciding between the role of care and doing other important things in life		0.835			
	Taking care of my patient has left me with no opportunity to take care of other matters of life, including education and work		0.657			
	I feel that my patient is too dependent on me		0.791			
Inadequate social support	Excessive hospital visits have disrupted other aspects of my life		0.772			
	There is no formal training for me in the hospital despite my frequent hospitalizations			0.713		
	There is no radio or television education on how to care for my patient			0.697		
	Books that simply describe the disease, its symptoms, and how to control it are not available			0.672		
	There are specialized centers for hemodialysis patients to help and educate me and my patient			0.761		
	Other family members accompany me in caring for me			0.832		
	Other family members and friends help me move my patient and bring him to the hospital			0.763		
	When I go to the doctor's office, he guides me in a good mood and by allocating appropriate time in how to take care of my patient			0.677		
	At work, they work with me to take care of my patient and bring him to the hospital			0.702		
	I feel lonely and helpless most of the time			0.723		
	The lack of welfare facilities in the hospital makes me tired			0.847		
	The costs of the patient's regular travel to the hospital are not covered by insurance			0.614		
Confusion and ambiguity	At the hospital, the nurses do not pay enough attention to my and my patient's requests			0.731		
	I have many questions about my patient's future condition				0.882	
	I have seen several doctors to cure my patient				0.732	
	I am worried about the future status of my patient				0.597	
	I'm worried about trying to leave my patient alone for a moment				0.593	
	Lack of written training by the medical system confuses me in dealing with my patient's condition				0.524	
	Due to the lack of information about my patient's condition, I frequently see different doctors				0.737	
	I am confused because I do not know what will happen to my patient				0.704	
	Different doctors' diagnoses have made me distrust the accuracy of the doctor's diagnosis				0.838	

*Contd...*



**Table 4: Contd...**

Dimension	Item	1	2	3	4	5
Lack of adaptation skills	Smoking or sedatives will help me					0.674
	I will try to find a better solution to my problems					0.797
	I will not accept what happened					0.665
	I use the assistance and advice of others					0.851
	I try to look at my problems from a positive perspective					0.563
	I criticize myself					0.704
	I plan and set goals to do anything					0.691
	I can feel the sympathy and support of my loved ones					0.874
	I try to adapt to external realities and events					0.871
	I will think about the good things that have happened in my life					0.572
	I will do things that make me think less about things like watching TV, reading, sleeping, shopping, going to the movies					0.753
	I try to express my feelings about this					0.771
	I will blame myself for what happened					0.807
	I pray and worship					0.677

PCTQHFC= Perceived care tension questionnaire for hemodialysis patients caregivers

**Table 5: The reliability of perceived care tension questionnaire for caregivers of hemodialysis patients (n=300)**

Factor	interclass correlation coefficient	Cronbach's alpha coefficient
Emotional exhaustion	0.703	0.764
Care burden	0.733	0.783
Inadequate social support	0.831	0.811
Confusion and ambiguity	0.809	0.698
Lack of adaptation skills	0.876	0.782
Total	0.921	0.911

to cope with stressful situations and situations that assist them in delivering patient care, establishing proper communication with the patient, reducing stress and care tension, and adapting to the caring role.<sup>[49]</sup>

In this regard, studies show that whenever a person is affected by stressful conditions, effective adaptation can protect them against physical and mental damages and problems, and the coping skills of caregivers play a determining role in how to relieve their stress and improve their mental health.<sup>[47,50]</sup>

In this regard, Cambell showed that care tension on elderly parents of patients with end-stage renal failure who care for them leads to feelings of guilt, frustration, loneliness, and loss of freedom to perform individual activities.<sup>[51]</sup>

The study of Wicks *et al.* showed that the quality of life of caregivers of patients with end-stage renal failure depended on disease, care and family factors, and that the tension on caregivers of these patients remained high for up to 6 months after kidney transplantation.<sup>[52]</sup>

Measuring the care tension of caregivers by a valid and stable tool can lead to preventive and early interventions.

Therefore, standard tools are required to evaluate the effectiveness of evidence-based programs and document them. Besides that, the questionnaire designed in the present study is specific to patient caregivers. There are various tools currently available to measure care burden, which is one of the dimensions of the studied questionnaire,<sup>[53,54]</sup> but there is no specific tool that can assess the care tensions of caregivers, particularly those of hemodialysis patients.

However, the questionnaire designed in the present study can be used to measure the care tension of caregivers due to its specificity. Performing the test-retest and calculating intra-class correlation showed that this tool had acceptable stability.<sup>[55]</sup> In this study, inductive (qualitative) and deductive (literacy review) methods were used to develop the tool. The inductive method is appropriate when the conceptual basis for the intended construct and its domains have not been well defined to draw the items on their basis. In the present study, a deductive method was used to develop the items. If the deductive method (literature review) is accomplished appropriately, it can be ensured that the content validity of the tool will be ultimately fulfilled.<sup>[56]</sup> The PCTQHFC consists of 52 items. It should be remembered that tools that have a sufficient number of appropriate words can accurately assess the various dimensions of the concept in question.<sup>[57]</sup> To achieve the desired internal correlation, at least three items are required for each structure.<sup>[23]</sup> In the present study, the first dimension includes 8 items, the second dimension has 9 items, the third dimension has 12 items, the fourth dimension has 8 items, and the fifth dimension has 14 items. After drawing the items, the scale of answers to each item or question should be determined. The scoring scale can be in the form of good and bad, right and wrong, agree and disagree, or as a ranking scale such as the Likert scale.<sup>[58]</sup> Currently, the 4-point Likert

**Table 6: Spearman's rank correlation coefficient between the factors of perceived care tension questionnaire for caregivers of hemodialysis patients**

Factor	Emotional exhaustion	Inadequate social support	Care burden	Confusion and ambiguity	Lack of adaptation skills
Emotional exhaustion	-	0.711	0.694	0.655	0.736
Inadequate social support	0.68	-	0.923	0.798	0.87
Care burden	0.603	0.808	-	0.811	0.719
Confusion and ambiguity	0.799	0.811	0.787	-	0.816
Lack of adaptation skills	0.736	0.722	0.808	0.789	-
Total	0.756	0.885	0.898	0.811	0.863

scale (very low to very high) was used. To develop or administer a tool, it is very important to pay attention to the psychometric quality of the tool. The two main psychometric characteristics of a tool are validity and reliability,<sup>[57]</sup> both of which were investigated in the present study. The validity itself has three main constituents, including face, content, and construct. The validity of the tool includes internal consistency, stability, and equivalency.<sup>[59]</sup> Some researchers also cite other criteria as features of the instrument's psychometric measurements, which include the ceiling effect and the floor effect,<sup>[55]</sup> all of which were used to conduct psychometric investigation of the instrument developed in the present study. It should be noted that the availability of quantitative methods to investigate content and face validity should not lead to disregarding the qualitative method to investigate these two types of validity. In fact, first of all, both for face validity and for content validity, a qualitative method must be performed.<sup>[59]</sup> In this study, both qualitative and quantitative methods were used to investigate face and content validity. To determine the content validity by the qualitative method, a number of experts with knowledge and experience in the field of the subject measured by the instrument are required to, after careful study of the instrument, offer their corrective views on compliance with the grammar, use of appropriate words, appropriate ordering of the items, and appropriate scoring as written<sup>[60]</sup> Factor analysis aimed to determine the dimensions of the questionnaire, is in fact a constituent of the construct validity, which Mokkink *et al.* refer to as construct validity.<sup>[61]</sup>

If there is no presupposition about the dimensions of the instrument, exploratory analysis will be performed. Prior to the EFA, the KMO test and Bartlett's test of sphericity were performed. The KMO coefficient indicated that the sample size was satisfactory for the analysis.

Bartlett's test of sphericity was also significant and indicated that factor analysis was appropriate to identify the model's construct.<sup>[62]</sup> The results of factor analysis showed that (HFCPCTQ) was multidimensional and measured the perception of care tension in the caregivers of hemodialysis patients. The results regarding the internal consistency of the instrument showed that the obtained coefficients for all

factors were higher than the recommended value of 0.7 for accepting the internal consistency of one factor.<sup>[63]</sup> Moreover, Cronbach's alpha coefficient of the entire questionnaire was 0.92, which indicates its acceptable reliability of the internal consistency. (PCTQHFC) is one of the first tools designed based on the principles of instrument development and according to the context and nature of patient care. In the present study, through a qualitative study, it was ensured that the designed items fit the context. In this study, the validation process (PCTQHFC) was based on the recommended standards,<sup>[64]</sup> which corresponds to the main validation criteria. In this study, in addition to qualitative methods, quantitative methods that provide more objective results were used to investigate face and content validity. In the process of designing these tools, the target group for which the tool was created were involved, and this is one of the important things in validating the tool. Therefore, it is recommended to use this tool to measure care tension among hemodialysis patients. Caregivers themselves are hidden patients who suffer severe damage to their physical and mental health as a result of physical and emotional tensions due to caregiving and decreased attention to their own health and self-care, so that decreased physical health and early death have been reported among caregivers. Researchers have found that family caregivers experience many adverse physical consequences as their patient's illness progresses, so that elderly spouses who had the experience of caring for their patient as caregivers had a 63% higher mortality rate than their peers and noncaregivers.<sup>[65]</sup>

The lack of health in caregivers is largely due to the fact that they feel that they are tolerating substantial care burden. The care burden of caregivers is largely related to their own poor health and the increase in high-risk health behaviors such as overdose.<sup>[66,67]</sup> Caregivers are always at risk for fatigue and sleep disorders, poor immune system function, inappropriate response to seasonal flu, delayed wound healing, increased insulin and hypertension, dyslipidemia, and increased risk of cardiovascular disease.<sup>[68]</sup>

The results of this study help to explain the dimensions of the concept of care tension specifically in hemodialysis patients; The questionnaire designed in this study is a scientific, cultural-oriented and psychometric

questionnaire to monitor care tension in hemodialysis patients; and the results of this study can help to continue applied research and science production and increase the scope of knowledge in the field of care tension in caregivers of hemodialysis patients. In this study, the items that are expressed negatively and positively were used. The use of these items is due to the argument that they can reduce the pattern of response.<sup>[31]</sup> It is important to note that in this study, both negative and positive items were used. The use of these items is due to the argument that they can reduce the bias of response pattern.<sup>[23]</sup> Also, it should be noted that our questionnaire is a self-report paper-and-pencil tool. Therefore, the answers may be subject to the personal respondent's interpretation of the items, which may not be what the designer of the questionnaire expects. Sampling in the quantitative phase was conducted by available method that may lead to samples from which the generalization of statistical inference to the general population is not very accurate.

### Conclusion

The results of the factor analysis showed that PCTQHFC was multidimensional and measures the perception of care tension in the caregivers of hemodialysis patients. It is a culturally appropriate measure with strong psychometric properties. Therefore, researchers, health-care providers and community health policymakers can plan for and implement interventions to change the attitude of caregivers and to reduce care tension by analyzing the situation, needs assessment and identifying mental challenges and the consequences of understanding care tension. Due to cultural differences in the use of this questionnaire its validity and reliability should also be evaluated in other regions.

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### Conflicts of interest

There are no conflicts of interest.

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