Original article

Designing and Psychometric Properties of Coping Strategies Scale for Family Caregivers of Hemodialysis Patients

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SUMMARY

The present study tries to design and evaluate the psychometric properties of coping strategies scale for family caregivers of hemodialysis patients. This study consisted of two phases: phase one was a qualitative study to analyze the experiences of coping strategies of hemodialysis patients' family caregivers' (N = 14). Then, the items were extracted from the interviews and the literature. Phase two was a psychometric assessment including face validity, content validity, construct validity (N = 245) and reliability. In phase one, 89 items were extracted and after face and content validity, 56 items remained. Construct validity of the scale, based on exploratory factor analysis, removed another 22 items. The remaining 34 items contained nine subscales (active coping, positive thinking, appeal to spirituality, help seeking, altruism, acting out, self-blaming, seeking isolation, and intentional forgetting). The reliability of the scale with Cronbach's alpha was 0.91 and its stability was obtained through test-retest (ICC = 0.9). Coping strategies scale for family caregivers of hemodialysis patients has an acceptable validity and reliability.

The tool can be used to assess effective and ineffective coping strategies in family caregivers of hemodialysis patients that may be useful for facilitating management and education of efficient coping strategies to family caregivers of hemodialysis patients.

Key words: coping strategy, family caregivers, hemodialysis, scale, validation studies

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INTRODUCTION

Chronic kidney disease is a serious and expanding health problem with a high rate of morbidity and mortality (1). According to data published in 2016, it is estimated that 752.7 million people worldwide suffer from chronic kidney disease, about 3 million of whom were receiving dialysis therapy (2). The number of hemodialysis (HD) patients in the Iran was 25,000 in 2013 (3). Although HD treatment improves survival and life expectancy in patients, it is featured with numerous problems for the patient. An HD patient needs to adhere a strict diet and medication with many restrictions in terms of liquids and foods that they are allowed to use (4 - 6).

The HD patients are exposed to severe stresses like those of all other chronic patients or even worse. The effects of chronic diseases not only disrupt patients' life, but also create many challenges for caregivers (7). Family of patients with end-stage renal disease (ESRD) should provide support and care for HD patients at home and in outpatient centers like HD wards. Considerable mental, physical, and social stresses are experienced by HD patients' care-givers, which result in several problems like depression, anxiety, and burnout (8).

Stress appears when an individual faces events that threaten their mental and physical health. Experiencing life-threatening chronic diseases is one of the stressful events for individuals and their families. These patients need to adopt coping strategies to achieve an acceptable level of physical, mental, and social performance (9). Having a systemic view of the family, a problem for a member of the family affects the rest of the family as well (10 - 13).

Family is the best source of care for HD patients and given the long process of kidney failure, emergence of new needs, and major changes in normal life style and routine, family members of these patient experience numerous stresses. In this regard, the coping skills play a notable role in dealing with the challenges and improving mental health of family members (14).

There are several general tools to assess coping strategies such as Folkman and Lazarus Coping Strategies Inventory (15). This Inventory contains 66 items that are used to categorize problem and emotional-based coping strategies. Another tool that is widely used is Carver coping inventory with 60 items

that is based on problem and emotional-based coping strategies as well (16).

These two tools have too many items that make them tedious and troubling for respondents to fill in. In addition, these two tools are general tools. Therefore, researchers seek new tools that are specially designed for caregivers of HD patients. Unfortunately, our search for such a tool yielded no result. Therefore, given the clear difference between the available tools and lack of a special questionnaire for coping strategies in family caregivers of HD patient based on Iranian culture, it is essential to design a scale with such specifications. The present study is an attempt to design and assess psychometric properties of coping strategies scale for family caregivers of hemodialysis patients.

PARTICIPANTS AND METHODS

This study was carried out based on an exploratory sequential mixed approach in two qualitative and quantitative phases.

Phase one: Generation of item

Item generation was carried out simultaneously in two stages. At first, the qualitative content analysis from the interviews with 14 family caregivers of HD patients was done to elaborate on coping strategies. Selection of the participants with rich information was continued until data saturation. Maximum diversity in the participants in terms of gender, age, kinship relationship, and HD duration was observed. The interviews would be started with general questions like "Tell us about your life experience and coping with hemodialysis problem of your patient." Such questions would be followed with "how do you deal with hemodialysis problem of your patient? And what is its meaning?" The interviews term ranged from 45 to 75 mins.

Qualitative data analysis was done based on conventional content analysis following Graneheim and Lundman's approach (17). To ensure data rigor, four criteria of creditability, dependability, confirmability, and transferability (fittingness) were used. In addition, to complete the item pool, an extensive literature review was conducted.

Phase two: psychometrics assessment

Face validity

Both qualitative and quantitative methods were applied to assess face validity in family caregivers of HD patients. The sample groups in this stage consisted of 10 family caregivers of HD patients who were selected through convenient sampling.

In the qualitative method, the family caregivers were asked to comment on the difficulty of understanding the words or items or probable ambiguities or risk of misunderstanding in the items. In addition, the scale was provided to 11 experts in psychiatric nursing, psychology, and instrument design and HD nursing instructors. They were asked to comment on the difficulty, relevance, and ambiguity of each item. In the quantitative method, item impact phase was done to measure the prevalence and importance of items retained and revised from the initial item pool. For this purpose, the experts were asked "to what extent each item is necessary to measure coping strategy of family caregivers?" To answer this questions, a Likert's five-point scale was used (very important = 5; important = 4; relatively important = 3; slightly important = 2; unimportant = 1). The items with impact score = > 1.5 remained for further analyses (18). Item impact score of scale items was calculated by the following formula: Item impact score = frequency x Importance, where "frequency" refers to the number of individuals who scored an item 4 or 5 and "importance" refers to the mean score of importance of each item.

Content validity

Qualitative and quantitative approaches were used to determine content validity. Through qualitative validity, the experts were asked to comment about the grammar, the appropriate and correct word, applying correct and proper order of words in items and appropriate scoring.

In the quantitative method and to make sure that the most relevant and current content is used in the scale, content validity ratio (CVR) and content validity index (CVI) were used.

Content validity ratio (CVR)

The experts were asked to determine, for each

item, whether or not an item is necessary to represent the concept of coping strategies for family caregivers of HD patients'? To this end, the experts chose from three alternatives (necessary, useful but not necessary, and unnecessary). The CVR varies between -1 to 1. The higher score indicates the stronger agreement among the experts. The formula of content validity ratio is CVR = (Ne - N/2) / (N/2).

"Ne" refers to the number of experts who chose "necessary" and "N" is the total number of experts (19). The numerical value of CVR was determined based on Lawshe's table (Lawshe, 1975) modified by Ayere and Scally (20).

In our study, the number of experts was 11, and if CVR is greater than 0.636 an item is acceptable at a significance level of 0.05.

Content validity index (CVI)

This index was measured specifically for each item (item - CVI) and for the whole scale (scale – CVI). Fifteen experts were asked to express their opinions based on a Likert's four-point scale (completely relevant, relevant, relatively relevant, and irrelevant). Minimum acceptable level for each item was 80%.

To determine SCVI, average approach (SCVI/ average) was used i.e. the total CVI of items was divided by the number of items. For the newly designed tool, an agreement level above 80% among the experts is recommended. That is, an item is acceptable when the ICVI is higher than 79% and the item should be revised if the obtained ICVI is between 70 and 79. Items with ICVI < 70 should be removed.

Construct validity

To determine construct validity of the scale, exploratory factor analysis (EFA), as the most widely used method, was adopted to categorize the items. The sample size for EFA, based on the rule of thumb, is the ratio between variables or items and participants. Monro cited Brown and Knapp that at least three participants are needed for each variable. From another viewpoint about the sample size, which is based on correlation, 100 to 200 participants are enough for most of purposes (21). Thereby, 245 questionnaires were distributed among family caregivers of HD patients to examine construct validity.

In factor analysis, a principle component analysis (PCA) with Equamax rotation was used with the following criteria: eigenvalues higher than 1.0 and factor loading higher than 0.4.

Reliability

Internal consistency and stability of the scale were examined in this stage. To ensure the reliability, Cronbach's alpha was used (minimum acceptable α = 0.7) for internal consistency and test/retest method (two-week interval) was used to examine stability of the scale.

RESULTS

Phase one: Generation of item

The data collected through interviews with 14 family caregivers of HD patients were used for content analysis and elaborate the concept of on coping strategies. The participants argued that coping strategies is mostly a subjective concept and affected by different factors such as active coping, positive thinking, appeal to spirituality, help seeking, altruism, acting out, self-blaming, seeking isolation, and intentional forgetting. These nine concepts were categorized into two general categories of efficient strategies (active coping, positive thinking, appeal to spirituality, help seeking, and altruism) and inefficient strategies (intentional forgetting, seeking isolation, self-blame, and acting out).

Using the extracted concepts and literature review, an item pool was formed and after removing, mixing, and revising similar and repetitious items using experts and research team members' opinions, 89 items remained in the study. The items were designed with a five-point scale (always, very often, sometimes, rarely, never). The scale does not yield a total score, so that the higher the score the higher the frequency of using coping strategies.

At the end of this phase, coping strategies scale for family caregivers of hemodialysis patients was designed with 89 items based on qualitative phase and literature review results. Psychometric properties results are further discussed in the following sections.

Phase two: psychometrics assessment

Face validity

As noted, face validity can be determined through qualitative and quantitative methods. To determine face validity, 10 items were revised based on family caregivers' opinions in the qualitative phase. In addition, the eleven experts were asked to express their opinions about the necessity of each item. Through quantitative method, face validity was determined through calculating the "item impact score," which was higher than 1.5 for each item. As all the items had an impact score > 1.5, therefore, with making changes in 10 items, all the 89 items entered content validity stage.

Content validity

Content validity was examined through qualitative and quantitative methods.

Qualitative content validity

Based on the comments by experts, 21 items were removed due to similarity in meaning. In addition, some of the items were revised and eventually, 68 items remained in the scale.

Content validity ratio (CVR)

Out of 68 items, CVR of 13 items was lower than 0.636. However, out of these 13 statements, four out of them remained in the tool in the scale due to the importance of the topic and consensus of opinions among the research team members. In some cases, experts might have come to conclusion that an item did not measure the intended construct and later the opposite was proven. Therefore, while the experts' opinion is one of the ways to check validity, it's not the only way and the research team can also make decisions based on the importance of the items (19). With removal of nine items, 59 items remained for CVI stage.

Content validity index (CVI)

In measuring CVI, Scale, Content Validity In-

dex was 0.97, which is highly acceptable and 56 items had CVI > 0.8 (with high Kappa coefficient) and only three items were removed in this stage. After making the changes based on face and content validity assessment, 56 items remained in the study and entered the next stage.

Construct validity

Participants in construct validity phase were 245 family caregivers of HD patients. Table 1 lists the

demographics of the participants in the quantitative phase.

To check the adequacy of the participants for EFA, Kaiser Mayer-Olkin test was used (KMO = 0.843, Chi-squared = 14569.219, df = 820, P value = 0.000). According to Munro (21) when KMO value ranges from 0.80 to 0.90, EFA can be used for the data

After performing principle component analysis with varimax rotation according to the Eigen values and Kaiser Criterion (factor coefficients > 0.5), finally 34 items in nine factors remained (Table 2).

Table 1. Demographic characteristics of caregivers

Demographic	n	%	
characteristics			
Age			
<40	27	11.03	
41-50	54	22.04	
51-60	117	47.75	
>60	47	19.18	
Gender			
Female	124	50.62	
Male	121	49.38	
Education level			
Literate	45	18.36	
Primary school	115	46.94	
High school	61	24.9	
University	24	9.8	
Occupation			
Working	151	61.63	
Non-working	94	38.37	
Dialysis duration	mea	SD	
of patients (years)	n		
	5.12	2.61	

Table 2. The subscales and items of coping strategies scale for family caregivers of hemodialysis patients

Subscales	Items		
	1. I do not think about the problems caused by the disease.		
Intentional	2. I keep myself busy to avoid thinking about the problems.		
forgetting	3. My problems are still there, but by not thinking about them, I try to make		
	it easier for myself.		
Seeking	4. I surrender to the problems.		
isolation	Because I have no hope for solving the problems, I do nothing.		
Self-blame	I keep blaming myself because of failure to look after my patient.		
	7. I feel regret because of a delay in seeking medical help for my patient.		
	8. I cry when I am alone.		
Acting out	9. I cry out when dealing with others.		
	10. I have an aggressive behavior with others.		
	11. I have accepted stressful events as a part of the life.		
	12. I make plan for handling extra tasks.		
Active coping	13. I face the problems and try to find alternative solutions.		
	14. I try to solve the problems with patience.		
	15. I do my best.		
	16. I try to have an optimistic view to the problem and keep my spirits up.		
Positive	17. I compare myself with those in worse conditions.		
thinking	18. I try to adapt to the problems and keep my humorous spirit.		
	19. I hope for finding a treatment in the future.		
	20. I trust in God in the face of hardships.		
Appeal to	21. I rely on Imams in the face of hardships.		
spirituality	22. I actively participate in religious activities.		
	23. I consult with a clergy.		
Help seeking	24. I try to collect information from others who have the same problem.		
	25. I collect the required information from health personnel.		
	26. I try to collect information from the Internet.		
	27. I receive financial and care supports from the family members.		
	28. I try to use the services provided by support associations like different		
	educational classes.		
	29. I seek emotional support from family members and friends.		
	30. I refer to physicians about the medication.		
	31. I place myself in my patient's shoes to understand his/her problems.		
Altruism	32. I give up my interests and joys for my patient's sake.		
	33. I try to keep my family members away from my problems.		
	34. My patient's needs are more important than my own.		

Reliability

Internal consistency

Cronbach's alpha for the whole scale with 34 items was 0.91. In addition, Cronbach's alpha was acceptable for all the subscales (Table 3).

Table 3. Cronbach's alpha and intraclass correlation coefficient (ICC) for the scale and the subscales

Subscale of hemodialysis patients family caregivers' coping strategies	Cronbach's alpha	ICC*
Intentional forgetting	0.91	0.88
Seeking isolation	0.89	0.89
Help seeking	0.93	0.93
Altruism	0.93	0.92
Acting out	0.89	0.89
Appeal to spirituality	0.97	0.94
Active coping	0.94	0.93
Positive thinking	0.91	0.91
Self-blaming	0.87	0.89
Total	0.91	0.9

^{*} P value < 0.001

Test-retest method

The test-retest reliability of the scale was estimated using the intraclass correlation coefficient (ICC). Test-retest was performed with 20 participants and a two-week interval. The ICC of the scale based on test- was 0.907 (Table 3).

DISCUSSION

Regardless of the purpose, scales and other measurement tools need to meet specific standards. There are at least four minimum standards necessary for the adequate evaluation of a scale for use in research. These standards include at least having one type of content validity, one type of construct validity, and two types of stability such as internal consistency and test-retest (18). In this study, to design and assess the psychometrics of the tool, we used two methods to determine face validity, two methods to determine content validity, one method to determine construct validity, and two methods to determine reliability. In this study, the researchers concluded that the extracted coping strategies can be categorized into effective and ineffective strategies. The effective strategies include active coping, positive thinking, appeal to spirituality, help seeking, and altruism. The ineffective strategies include intentional forgetting, seeking isolation, self-blame, and acting out.

The majority of studies have categorized coping strategies based on Lazarus and Folkman's coping and stress model (22, 23). According to Avcioglu and Karanci, siblings of patients with schizophrenia used problem-focused coping and social support (22). Marques et al. (10) conducted a study to determine coping strategies of family members of HD patients in Brazil. They argued that the most common coping strategy by family members was escape-avoidance. That is, the family members preferred not to face the situation. In addition, social support strategy was the second most used strategy, which meant that the family members had a positive attitude towards receiving support from others and consulting others to solve the problems.

Although Lazarus and Folkman's coping and stress model is a comprehensive model, some subscales are not covered by it. Specific elements such as active coping, appeal to spirituality, altruism, acting out, self-blame, and intentional forgetting belong to the new domains highlighted by the present work.

Intentional forgetting, as the first aspect, was covered by three items. As demonstrated by these items, people try to intentionally forget their scary and painful feelings, desires, and memories or push them to their unconscious mind. Intentional forgetting prevents penetration of unconscious desires to the conscious mind. In fact, these feelings are not lost forever with intentional forgetting. They are thought to exist in one's unconsciousness and may re-enter the conscious mind when the person's consciousness is weak, such as during sleep, psychoanalysis, hypnotism, etc. According to Freud, these tendencies constantly affect one's behavior (24).

If this mechanism brings success, stress level decreases; however, anxiety can be expected if forgetting does not decrease the stress level (25). Forgetting can be a prerequisite of other coping strategies, that is, unacceptable and stressful impulses are suppressed and then defensive mechanism are activated.

The second aspect in the scale was seeking isolation, which was covered by two items. Given the questions of this aspect, the individual tries to decrease the frequency of encountering stressful factors. This coping strategy can lead to quit trying to achieve a goal in which worrying factors are

found. Seeking isolation is extensively related to helplessness. It appears that this strategy is implemented when the individual expects very poor results. Based on this aspect, the individual performs activities that are far away from thinking about stressful behaviors or goals. This strategy includes alternative activities that keeps one's mind away from the problem. Although this strategy leads to coping in some cases, such responses mostly prevent coping (26, 27).

The third aspect was self-blame, with two items. Self-blame means to find oneself responsible for bitter experiences. An individual feels guilt when they blame themselves for an event. Strong guilt feeling might lead to mental diseases like depression (28). Experiencing self-blame emotions such as guilt, shame, humiliation, and self-disgust intensifies mood disorders (29). In active emotional coping skills, the person expresses their emotions openly to cope with stress. On the other hand, in passive emotional coping skills, stressors are faced through emotional suppression or self-blame (30, 31).

The fourth aspect of the scale was acting out covered with three items. Acting out is a behavioral response to an unconscious stress that leads to relative and temporary alleviation of internal stresses. That is, to achieve alleviation, the individual reacts to the situation (32). Christopher et al. showed that acting out as a coping strategy is common among patients with traumatic brain injuries (33).

The fifth aspect of the scale was active coping with five items. Active coping is a general term to refer to many behavioral and cognitive strategies where the individual actively manages a stressful situation and emotional and physiological responses (34). A qualitative study by Cutillo et al. (35) on coping strategies in caregivers of newly diagnosed pediatric brain tumor showed that the most common coping strategies were active coping, avoidance, emotion-focused, and spiritual coping. Active coping consists of sub-themes such as information seeking, openly communicating emotions, celebrating small victories, planning and maintaining normalcy.

The sixth aspect was positive thinking with four items. Positive thinking is the way or outcome of the mind positive focus on a constructive and good thing. Therefore, negative or destructive emotions and thoughts are eliminated. Optimistic psychology is mostly focused on strengthening one's abilities and merits (36). Bekhet et al. studied the effects of positive thinking on burnout of dementia

caregivers and behavioral problems of care-recipients. They showed that as positive thinking increased, the level of embarrassment and disruption went down in patents; self-criticism and depression decreased in caregivers as well (37).

The seventh aspect of the scale was appeal to spirituality, covered by with four items. To elaborate on the findings about using religious approaches, Allport argued that religion and religious orientation are comprehensive issues with organized and internal principles. In addition, individuals with religious orientation have genuine belief in their religious trainings and that only real religion can improve mental health. This does not mean that all individuals who claim to be religious have a healthy personality (38). Having some objective in life, feeling attached to God, hope in God's help in harsh situations in life, and having social and spiritual supports all are the methods that religious individuals rely on to deal with stressful life events (39). Having faith in God, faithful individuals see God next to themselves in harsh situations and rely on Him. Such reliance helps faithful individuals to use spiritual beliefs in the face of hardships. Faith in God not only brings spiritual peace in the family but also helps individuals to adapt to their problems and accept them easily. In Babamohamadi et al (40), reliance on religious beliefs in the face of hardships created mental and spiritual peace in patients with spinal cord injury. Reliance on religious beliefs appears in different forms such as reliance on Imam and prayer.

The eight aspect was help seeking covered with five items. When individuals genuinely rely on a specific individual in their social network for help during stressful situation, the support should be provided in cooperation with the recipients of support. The point is that the support by the network members should meet the needs of the receivers (41). Help seeking in general includes social, information, and emotional supports.

Social support can be defined as one's perception or experience of being loved, looked after, valued, and being as a part of a social network featured with supports and commitment (42, 43). Information support happens when an individual helps another one to have a better perception of a stressful situation. It determines what kind of coping resource and strategy is best to deal with such a situation. Information support includes useful guidance, information, and instruction to cope with major life

events and to find a meaning in life and the world (44). Emotional support, on the other hand, includes providing affection, love, attention, and emotional support so that the receiver feels as a valuable individual (45, 46). This type of support can be provided by individuals that the receiver feels intimate enough to talk to them about problems. It is generally provided by family, friends, colleagues, neighbors, and significant ones through expressing love, affection, and attention. Emotional support results in creating emotional well-being (47). Sari et al. tried to examine the relationship between family support, coping strategies, and anxiety in patients under chemotherapy. They showed that family support has a direct and positive relationship with using Problem-Focused Coping strategies (48).

The last aspect of the scale was altruism, which means a motivation for selfless help and concern for the welfare of family members or others (49). In altruism, an individual helps others constructively without expectation of reward. Empathy is an important motivation for altruism. Empathy begins and further develops socio-emotional relationships between individuals and thus enhances their positive personal growth (50).

Still, Williams et al. reported that male caregivers to ESRD patients had positive care experience with subthemes like commitment and feeling satisfied (51). Altruism has deep roots in Iranian culture. Iranian people are not inconsiderate towards their families, relatives, and friends. This cultural difference may explain differences between the proposed scale (altruism aspect) and similar scales.

Through creating a better and more accurate perception of coping strategies of HD patients' family caregivers, the scale can help the providers of health services to provide better preventive, care, and therapeutic services to the family caregivers of hemodialysis patients. Having a clear perception of coping strategies of family caregivers of HD patients helps managers and officials of the health system to

introduce more efficient plans. Such plans should motivate nurses to examine and manage coping strategies of the family caregivers. They should implement interventions about coping strategies to improve the quality of cares received by patients. Nurses are the best providers of care and play an important role in promoting public health. The role of nurses has included clinical nursing practices, consultation, follow-up treatment, patient education and support and illness prevention (52 - 54). Therefore, they can have an active role in managing coping strategies of family caregivers of HD Patients.

CONCLUSION

Coping strategies scale for family caregivers of hemodialysis patients contains nine subscales, namely active coping, positive thinking, appeal to spirituality, help seeking, altruism, acting out, self-blame, seeking isolation, and intentional forgetting. The scale has 34 items with acceptable validity and reliability.

Ethics approval

The ethical concerns observed in this study included securing a permission from the authorities, briefing the participants about the objectives and nature of the study, reminding the participants of their right to willingly participate in the study and leave the study at any stage, assuring the participants of confidentiality of their information, anonymous publication of data, and obtaining permission from the officials (ethical code:

IR.SAVEHUMS.REC1397.006).

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Dizajniranje i psihometrijske karakteristike skale za procenu strategije suočavanja kod porodičnih negovatelja bolesnika na hemodijalizi

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SAŽETAK

Ova studija je pokušaj dizajniranja i procene psihometrijskih karakteristika skale za procenjivanje strategije suočavanja kod porodičnih negovatelja bolesnika na hemodijalizi. Studija se sastojala iz dve faze: prva faza bila je kvalitativna studija ca ciljem analize primenjenih strategija suočavanja porodičnih negovatelja bolesnika na hemodijalizi (N = 14). Stavke su zatim izvučene iz intervjua i literature. Druga faza bila je psihometrijska procena koja uključuje subjektivnu procenu vrednosti testa, validnost sadržaja, validnost konstrukta (N = 245) i pouzdanost. U prvoj fazi, izvučeno je 89 pojmova i, nakon subjektivno procenjene vredosti testa i validnosti sadržaja, ostalo je 56 pojmova. Na osnovu eksplorativne faktorske analize, validnost konstrukta isključila je još 22 pojma. Preostala 34 pojma sadržala su devet podskala (aktivno suočavanje, pozitivno razmišljanje, pozivanje na duhovnost, traženje pomoći, altruizam, loše ponašanje, samooptuživanje, samoizolaciju, i namerno zaboravljenje). Pouzdanost skale iznosila je 0,91, a stabilnost je dobijena putem testa-retesta (ICC = 0,9). Skala za procenu strategija suočavanja kod porodičnih negovatelja ima prihvatljivu validnost i pouzdanost.

Alati se mogu koristiti u proceni efektivnih i neuspešnih strategija suočavanja kod porodičnih negovatelja bolesnika na hemodijalizi.

Ključne reči: strategije suočavanja, porodični negovatelji, hemodijaliza, skala, validacione studije