



Original Article

Psychometric evaluation of the caring ability of the family caregivers of the patients in need of palliative care scale (CAFCPNPCS): A methodological study

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ABSTRACT

Background & Aim: Since family caregivers play an important role in providing care for patients in need of palliative care, it is important to focus on and examine their care ability in fulfilling the expected roles. Therefore, this study aimed to perform a psychometric evaluation of the *Caring Ability of the Family Caregivers of the Patients in Need of Palliative Care Scale (CAFCPNPCS)*.

Methods & Materials: The present study is methodological research that evaluates the psychometric characteristics of the CAFCPNPCS by measuring face validity, content validity, construct validity (confirmatory factor analysis and divergent validity), and internal consistency in 412 family caregivers of the patients in need of palliative care, who were selected through convenient sampling. The data were analyzed using SPSS 24 and LISREL 8.8.

Results: According to the confirmatory factor analysis, the 5-factor model with 31 items was confirmed with the values RMSEA=0.05, CFI=0.95, and GFI=0.88. The divergent validity was measured by the estimation of the correlation between the caring ability score with the care burden score (which was measured by Zarit Burden Interview) of the family caregivers of the patients in need of palliative care. Cronbach's alpha (α) was reported to be 0.85 for the whole scale and 0.781-0.852 for other dimensions.

Conclusion: CAFCPNPCS is a valid and reliable tool that can evaluate the caring ability of the family caregivers of patients in need of palliative care. Based on the results, it is recommended to utilize this scale to determine these caregivers' ability to provide care and to examine the effectiveness of interventions to improve the dimensions of their caring ability.

Introduction

Palliative care is an important part of integrated and people-centered healthcare services, which aims to improve the quality of life among terminally ill patients and their families through prevention, screening, early diagnosis, pain relief, and the assessment and treatment of physical, mental, spiritual and social issues (1, 2). It is estimated that more than 56.8 million people need palliative care every

year, 25.7 million of whom are in the last year of their lives. 78 percent of the latter group live in low- and middle-income countries. According to World Health Organization statistics, in the EMRO region, under 1% of the patients in need of palliative care receive this type of care (2).

Due to the complicated symptoms and problems, these patients gradually become dependent on the family caregivers who are the

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main source of support. The diagnosis of an incurable disease and the resulting changes sometimes disrupt the family system and require changes to include the patient's medical care needs in the daily routine (3). Although the onset of a chronic disease impacts the entire family, the responsibility of care provision usually rests with one family member, who is the primary caregiver (4, 5). Besides having to fulfill multiple roles, the main caregiver has to manage his/her mental concerns as well as the patient's concerns during the course of the disease (5, 6).

This care activity is often provided unexpectedly, without prior knowledge and preparation, which can negatively affect the quality of care and lead to a variety of physical, mental, social, spiritual, and financial challenges for caregivers, which usually remain unaddressed (7). In addition, the burden of care, limited activities, fear, insecurity, loneliness, the prospect of the patient's death, and the lack of emotional support will increase the risk of fatigue, vulnerability, and burnout among family caregivers (8). Therefore, neglecting caregivers' needs may lead to a low quality of life in them (6). Based on the results of a systematic review, it leads to physical and mental challenges, a lack of adaptation to caregiving challenges, and an information gap (9). Therefore, providing these complicated types of care demands the family's high knowledge and skills, and family caregivers' sufficient information on the disease and how to provide care for the sick family member (10).

Care providers should empower and support family caregivers and help them acquire the necessary knowledge and skills to provide quality care (10). The first step in supporting this group of caregivers is understanding their educational as well as their needs in providing care which is called caring ability (11). Measuring and evaluating their skills, as part of this concept, determines the required educational program (12). Caring ability is defined as the degree of applying care strategies while maintaining physical and mental health, care competence and preparedness, spiritual coherence, and economic status appropriate for addressing patients' care and treatment needs so

that care burnout and confusion are avoided if the caregiver can provide care (10).

Obviously, to investigate these abilities in the form of caring ability, it is necessary to have valid tools for the target population. Measuring the family caregivers' caring ability can determine their strengths and weaknesses and help professional staff plan more precisely in this regard (10). However, despite the need, a specific tool to measure the caring ability of family caregivers for patients requiring palliative care remained elusive. In 2020, Nemati et al. introduced the Caring Ability of the Family Caregivers of Patients with Cancer Scale (CAFPCPS). This scale was designed through mixed methods research, utilizing an exploratory sequential approach. While cancer is one of the 20 diseases necessitating palliative care, it's essential to recognize that each such disease possesses unique characteristics. These distinctions include variations in affected patient populations (infants, children, adults, elderly), disease types (communicable, non-communicable), and the development of specific or general complications (2).

Given these differences, the applicability of the CAFPCPS—originally developed for caregivers of cancer patients—to other diseases remains uncertain. For instance, when examining patients suffering from stroke, heart attack, and heart failure, some similarities to cancer in terms of population and non-communicability are observed. These parallels suggest that similar caregiving needs may exist among family caregivers for these conditions.

Therefore, it appears plausible that the CAFPCPS could be employed to assess the caring ability of family caregivers for patients in need of palliative care. Validating this tool may enhance our understanding of family caregivers' abilities, enabling healthcare providers to evaluate the effectiveness of interventions aimed at improving their caregiving ability for quality home care.

Therefore, this study was conducted to perform the psychometric assessment of the caring ability of the family caregivers of the patients in need of palliative care.

Methods

Study design

The current study is methodological research that investigates the psychometric properties of CAFPCPS among the family caregivers of patients in need of palliative care based on face and content validity, confirmatory factor analysis, divergent validity, internal consistency, and stability.

Study settings and participants

Data collection was done from March to July 2022. The sample consisted of Iranian family caregivers of patients in need of palliative care, including patients with cancer, heart failure, heart attack, and stroke, which are considered common conditions requiring palliative care according to the Global Atlas of Palliative Care (2). These caregivers were selected through convenient sampling. The inclusion criteria consisted of being able to read and write in Farsi, providing care for a patient in need of palliative care who was over 18 years of age with a Palliative Performance Scale (PPS) \leq 40, and having at least 6 months experience of providing direct patient care at home.

PPS is a tool designed to measure physical functional performance in palliative care patients. This tool evaluates five functional parameters including *the namely degree of ambulation, the ability to do activities and the extent of disease, the ability to do self-care, food and fluid intake, and the state of consciousness*. There are 11 levels of PPS, ranging from 0 to 100% in 10 percent increments for measuring the scores. Any decrease by 10%, represents a relatively significant decrease in the physical functional performance. For example, a person with a score of 0 is passed away, and a score of 100% is completely ambulatory and healthy (13).

Instruments

Data were collected through a demographic variables questionnaire, CAFPCPS, and Zarit Burden Interview (ZBI).

Demographic variables include age, gender, marital status, level of education, occupation, income, relationship with patient,

the length of care provision, and the patient's condition.

CAFPCPS has been developed by Nemati et al. (2020) and consists of 31 items in 5 dimensions: *effective role play* (12 items), *fatigue & surrender* (8 items), *trust* (3 items), *uncertainty* (4 items) and *caring ignorance* (4 items), which are scored on a 5-point Likert scale ranging from *completely agree* (5), *agree* (4), *no opinion* (3), *disagree* (2), *completely disagree* (1). The total score of the instrument was 155 with a maximum score of 31. The Cronbach's α is 0.93 for the whole scale and 0.705-0.933 for the dimensions. The internal consistency coefficient (ICC) of the instrument was 0.93 (10).

ZBI was developed by Zarit et al. (1986) to determine the mental burden of disease and has 22 items on a 5-point Likert scale consisting of *never* (0), *seldom* (1), *sometimes* (2), *most of the time* (3), and *always* (4). The sum of the scores obtained by each caregiver will determine the disease burden. The validity and reliability of this tool have been thoroughly examined in previous studies. It demonstrates acceptable content validity across all statements. Specifically, in the Content Validity Index (CVI) dimension, scores ranged between 0.7 and 1.0. The Intraclass Correlation Coefficient (ICC) stands at an impressive 0.958, affirming the tool's consistency. Additionally, the internal consistency has been confirmed through the calculation of Cronbach's alpha coefficient, resulting in a value of 0.86 (14).

In a separate study by Mirzaei et al., the reliability of this tool was assessed using both the retest coefficient and Cronbach's alpha, yielding a correlation coefficient of 0.92 (15).

Study processes

The research settings consisted of chronic disease clinics and the inpatient wards of the 3 selected referral hospitals. The family caregivers meeting the inclusion criteria were selected through convenience sampling to participate in the study. If they signed the written informed consent, they were given the demographic data questionnaire, the caring ability scale, and the ZBI.

Content validity and cognitive evaluation

While the Caring Ability of Family Caregivers of Patients in Need of Palliative Care Scale (CAFPCPS) was not developed from scratch, only its qualitative content validity was examined. To assess content validity, the CAFPCPS was administered to eight experts in the fields of palliative care and scale development, including faculty members from nursing and psychology schools. These experts evaluated the appropriateness of the scale items for patients requiring palliative care.

Additionally, for cognitive evaluation, the researchers enlisted ten family caregivers of patients in need of palliative care who met the research criteria. These caregivers completed the scale and provided feedback on the clarity and understandability of the items, as well as the time required to answer them. Based on their responses, no revisions were deemed necessary, as the items were found to be clear and understandable.

Construct validity

The construct validity was examined through two methods: performing Confirmatory Factor Analysis (CFA) and measuring divergent validity. CFA is a technique for structural equation modeling. In order to determine the goodness-of-fit, the maximum likelihood estimation (MLE) was done. There are several fit indices to decide about the appropriateness of the model. To perform CFA, a number of at least 250 samples are necessary for an accurate data analysis. With this number of samples, the approximation test can be done with a power of 0.80 using the root mean square error of approximation (RMSEA) for a model with a degree of freedom of 100 in structural equation modeling. In this study, the data of 412 samples were analyzed using LISREL V8.8 to determine whether the CAFPCPS items are valid indicators to examine the caring ability of family caregivers of patients in need of palliative care and the 5-factor model is approved to be used in this research population.

Considering that, according to the studies, high caring ability is associated with a low score of the burden of care (16, 17), the correlation coefficient between CAFPCPS scores and ZBI was calculated in order to evaluate the divergent validity.

Reliability

The internal consistency was investigated by calculating Cronbach's alpha for the whole scale and each of the 5 dimensions.

Ethical consideration

This study was confirmed by the Research Ethics Committee of the Cancer Research Center of Shahid Beheshti University of Medical Sciences under the code IR.SBMU.CRC.REC.1400.043. All methods were carried out in accordance with relevant guidelines and regulations. All experimental protocols were approved by the Cancer Research Center of Shahid Beheshti University of Medical Sciences. After the code of ethics was approved, the researchers obtained the necessary permits for sampling and presented them to the selected related centers. Then the research objectives were explained to all the participants. Data confidentiality privacy, and anonymous data analysis were observed in all the phases of the research.

Data analysis

CFA-related data was analyzed by calculating the fit indices including CFI, GFI, and RMSEA using LISREL 8.8. All the data related to the reliability of scales such as Cronbach's alpha and divergent validity coefficient were analyzed through SPSS 24.

Results

A total of 412 questionnaires were evaluated and statistically analyzed in this study. According to the data, 34.7% of the caregivers were 20-30 years old and 72.3% were female, of which 41.5% had 1 to 3 years' caregiving experience. Other demographic characteristics of the subjects are shown in Table 1.

Table 1. Demographics and characteristics of participants

	Variables	n	%
Age (year)	20-30	143	34.7
	31-40	109	26.5
	41-50	87	21.1
	51-60	53	12.9
	≥61	20	4.9
Gender	Female	298	72.3
	Male	114	27.7
Marital status	Single	118	28.6
	Married	185	44.9
	Widow	72	17.5
	Divorced	23	5.6
	Deceased	14	3.4
Educational status	High school	66	16
	High school diploma	152	36.9
	Academic	194	47
Job	Employed	145	35.2
	Unemployed	197	47.8
	Retired	42	10.02
	Disabled	28	6.8
	Spouse	122	29.6
Relationship with patient	Child	147	35.7
	Mother	50	12.1
	Father	81	19.7
	Other relatives	12	2.9
	Less than 1	171	41.5
Times caring (year)	1-3	142	34.5
	3-5	58	14.1
	5-10	21	5.1
	More than 10	20	4.9
	Chronic heart failure	81	19.7
Types of diseases	Cancer	149	36.2
	MI	88	21.4
	Stroke	66	16
	Diabetes	6	1.5
	Dementia/ Alzheimer	3	0.7
	Multiple sclerosis (MS)	8	1.9
	Other	11	2.7

According to the participants, no changes were made to the items while examining the content validity and cognitive evaluation of the tool.

The results of the confirmatory factor analysis showed that according to the scores of goodness of fit indices, the model has a favorable fit (Table 2).

Table 2. The values of CFA fit indices for the 5-factor model with 31 items

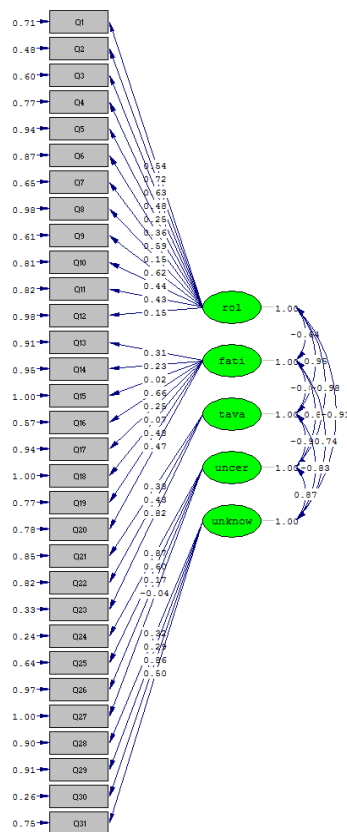
Model	X ²	df	χ^2/df	CFI	IFI	RMSEA	GFI	NFI	NNFI	RFI	SRMR
Factor analysis with 5 dimensions and 31 items	884.42	424	2.08	0.95	0.95	0.05	0.88	0.91	0.95	0.90	0.05

As seen in Figure 1, CFA results for the 5-factor model show that all dimensions have an acceptable correlation coefficient. Furthermore, based on the T-value test, all the relationships between dimensions and their items are significant and there is no heterogeneity (Figure 2).

Therefore, the desired model and its constituent concepts are acceptable according to the fit indices, where $\chi^2/df < 2$, $RMSEA < 0.08$, $CFI \geq 0.90$, $GFI \geq 0.90$ (26), and $NNFI \geq 0.90$ (27). In order to investigate the divergent validity, the correlation between the caring ability score of the family

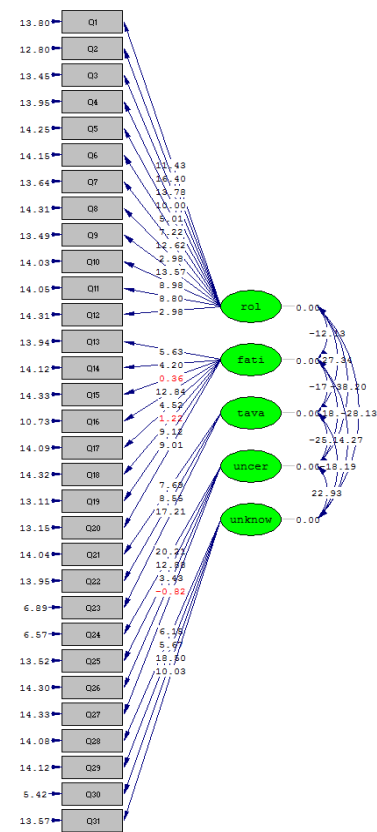
caregivers of the patients in need of palliative care with the score of the Zarit Burden Interview was determined as $r=-0.451$ ($P<0.001$). The internal consistency of all items in the original version of the CAFCPNCS tool was determined for a number of 412 samples. Cronbach's alpha

was reported as $\alpha=0.85$ for the whole scale and were separately for dimensions of effective role play (0.85), fatigue & surrender (0.83), trust (0.82), uncertainty (0.82), and caring ignorance (0.78). The Cronbach's alpha of the ZBI tool was calculated as 0.71 in the current study.



Chi-square=884.42, df=424, P-value=0.00000, RMSEA=0.051

Figure 1. CAFCPNCS standard estimation model for the 5-factor model with 31 items



Chi-square=884.42, df=424, P-value=0.00000, RMSEA=0.051

Figure 2. T-value for the 5-factor model with 31 items

Discussion

The increased number of patients in need of palliative care has caused many issues in the health systems, which apparently may be partially addressed by using the capacity of family caregivers. Since the assessment of their caring ability is the first step to designing empowerment programs, this study was conducted with the aim of the psychometric evaluation of the caring ability of the family caregivers of patients with cancer for family caregivers of patients in need of palliative care. Despite the fact that in the Iranian culture, taking care of sick people by family members is considered as a value (10), studies refer to caregivers' lack of familiarity and preparedness to play the role of the caregiver and the

acquisition of care knowledge and skills as an unmet need among caregivers (18).

The original version of CAFCPNCS, which was developed by Nemati et al. to assess the caring ability of the caregivers of patients with cancer (10) was the closest and most appropriate tool available to evaluate the caring ability of the family caregivers of the patients in need of palliative care, because the patients with cancer are one of the largest groups with the indications of palliative care.

The first dimension of CAFCPNCS is *effective role-play* with 12 items, expressing the appropriate performance of the family caregivers of the patients in need of palliative care including detecting and addressing the patient's care needs, emotional control over the family in the crisis caused by the disease and its outcomes, the ability

to make decisions and solve problems, encouraging the patient to participate in social activities and motivating the patient through psychological support (10). This dimension focuses on empowering the family and preparing them to play an effective role in care. Considering that patients need palliative care mostly at the end of life, the limited resources in healthcare centers for long-term care at the end-of-life stages as well as the absence of such centers (hospice) in the country on the one hand (19) and the patients' desire to receive care at home on the other hand (20), empowering family members to play an effective role in this regard has become very important (21).

In the dimension *fatigue and surrender*, which represents the negative outcomes of care, 8 items of the original questionnaire were retained. Due to the patient's stress and worry, this dimension covers a range of psychosocial and economic issues that can lead to fatigue and indifference in patient care (22). The importance of this dimension in measuring care ability is that even if family caregivers have the necessary care knowledge and skills, they need full support from others in the care process. Failure to meet these needs will affect not only the caregivers but also the entire care process. The pressure that caregivers experience as a result of the imbalance between care requirements and the available supportive resources to fulfill them will cause a constant and increasing burden of care during the course of the disease (23).

The third dimension of CAFCPNPCS is *trust* with 3 items, which has remained unchanged compared to CAFCPCS. This dimension is related to spirituality and finding meaning in life and indicates that one's spiritual beliefs can have an impact on coping with crises and solving the related problems and help his/her grow (24). Family caregivers use the meaning of life and trust in a higher power as a coping strategy to achieve goals, resolve conflicts, and adapt to the situation (25). They create a meaningful framework for the disease and the resulting suffering, which makes it easier for them to accept the existing condition. In Iran, due to the prevalence of Iranian-Islamic culture, patients and their caregivers somehow try to protect themselves from stress, disasters, and diseases by

having confidence in spiritual resources (26). A crisis may challenge one's religious beliefs and faith, or on the contrary, force him/her to use faith as a coping resource (46), leading to spiritual stabilization or "awakening" and coherence (27).

The dimension *uncertainty* has 4 items. Things like worrying about the patient and waiting for bad news reflect this uncertainty. *Uncertainty in illness scale* translated and validated by Sajjadi et al. (28) in Iran, includes concepts similar to this dimension, too. Uncertainty in disease includes "the patient or the family's inability to determine the meaning of disease-related incidents when they are unable to process these events or cannot specifically predict the disease outcomes due to insufficient symptoms (28). This is not simply the result of the complexity of the disease and its treatment; the lack of knowledge and not disclosing information about the disease can limit involvement in decision-making and lead to "decision paralysis".

Caring ignorance with 4 items refers to the caregivers' lack of awareness of the patient's care needs and not addressing these needs due to insufficient care knowledge and skills, which is considered to be one of the factors affecting the quality of patient care (10). Meeting care needs depends on factors such as caregivers' knowledge and skills. Therefore, in addition to examining the patient's care needs, professional caregivers should also guide the family in terms of access to proper and available resources and make a clear assessment of knowledge, skills, and the acceptance of caregiving roles in the family.

In order to investigate the divergent validity, the correlation between the scores of CAFCPNPCS and ZBI was defined, which showed that with an increase in caring ability, the burden of care decreases. The results of the study by Coppetti et al (2019) showed that family caregivers' caring ability increases when there is reduced care burden and stress (16). In addition, Abbasi et al. (2011) reported a significant and negative correlation between the burden of care and the ability to perform personal activities, which is consistent with the findings of the present study (29). One of the most important factors impacting the burden of care is the lack of knowledge, awareness, and necessary skills for patient care (30). Therefore, by teaching the

caregivers how to provide care for the patient at home and problem-oriented coping skills, they can be empowered to fulfill caregiving roles, and adapt to the responsibilities and changes in their lifestyle following the provision of care for the patient at home, resulting in reduced burden of care.

Reliability is the major concern when using a psychological test. Based on the results of the research, Cronbach's alpha was measured to be 0.78 for the whole tool, and 0.78-0.85 for its dimensions, which was acceptable. According to the results, the items of the scale are accurate, reliable, repeatable, and acceptable.

Study limitations

The patients in need of palliative care include a wide range of patients whose various needs may lead to differences in the dimensions of their family caregivers' ability to provide care. Therefore, it is suggested to conduct studies in different groups in terms of the type of disease and the geographical region.

Conclusion

This study was conducted with the aim of psychometric evaluation of CAFCPNPCS. The desired scale contains 31 items and 5 dimensions and provides the opportunity to evaluate the care ability of the family caregivers of the patients in need of palliative care in the Iranian culture. Based on the results of the study, it is recommended to use this scale to determine the caring ability of the family caregivers of the patients in need of palliative care and the effective interventions, in order to improve each dimension of caring ability and, in turn, to enhance the caring ability itself. The primary objective of validating this tool was to make it applicable for nurses, as they are frequently in direct communication with patients' families and play a crucial role in providing necessary training to caregivers. However, it's important to note that this tool can also benefit the entire palliative care team. Its diverse subscales encompass various dimensions of caregiver ability, including physical, psychological, social, and spiritual aspects. Since the purpose of providing palliative care is to improve the quality of life for the patient and the family, by measuring the care ability of the family caregivers of this

group of patients, care providers will be able to identify the educational needs, to find out what needs to be improved, and to develop an appropriate care plan.

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Conflict of interests

The authors declare that they have no conflicting interests.

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