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Construct Validity and Internal Consistency of a Malay Version of the FAMCARE Scale for Measures of Informal Caregivers Satisfaction

(Membina Kesahihah dan Ketekalan Dalaman Skala FAMCARE Versi Melayu untuk Penilaian Penjaga Tidak Rasmi Malaysia)

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ABSTRACT

Evaluating the satisfaction of caregivers is a highly subjective procedure and there is a need for a culturally appropriate, validated and sufficiently tested measurement tool to identify their needs in a clinical setting in order to improve the quality of care. FAMCARE is a self-report scale assessing patient/ caregivers' satisfaction with outpatient care. This study evaluated the validity and internal consistency of a Malay-language version of the FAMCARE scale amongst Malaysian informal caregivers. A total of 45 Malaysian informal caregivers in the outpatient oncology clinic, Hospital Universiti Sains Malaysia completed the questionnaire. Responses were checked for construct validity (including exploratory factor analysis to check the factor structure of the scale) and internal reliability. The 20 items of the FAMCARE scale were subjected to principal axis factoring (PAF) using SPSS, starting with assessing suitability of the data for factor analysis. Correlation matrix showed the presence of many coefficients of 0.3 and above. The Kaiser–Mayer-Olkin value was 0.79 and the Barlett's Test of sphericity was highly significant (p<.001). PAF showed the presence of four components with eigenvalues exceeding 1, explaining 60.8% of the cumulative variance. The items were loaded in four domains with satisfactory inter-factor correlations. The general FAMCARE questionnaire as a whole was found to have high internal reliability (Cronbach's α = 0.93). The Malay-language version of the FAMCARE scale appeared as a valid and reliable tool for assessing informal caregiver's satisfaction in outpatient settings, although it would be preferable to eliminate weak items which have low factor loading.

Keywords: Caregiver satisfaction; construct validity; informal caregiver; reliability

ABSTRAK

Menilai kepuasan penjaga ialah satu prosedur yang sangat subjektif dan alat penilaian yang sesuai dengan budaya, sahih, dan cukup teruji adalah diperlukan untuk mengenal pasti keperluan mereka dalam tetapan klinikal untuk meningkatkan kualiti penjagaan. FAMCARE ialah satu skala laporan kendiri yang menilai kepuasan pesakit/ penjaga dengan penjagaan pesakit luar. Kajian ini menilai kesahihah dan kekonsistenan dalaman skala FAMCARE versi Bahasa Melayu dalam kalangan penjaga tidak rasmi Malaysia. Sejumlah 45 penjaga tidak rasmi Malaysia di klinik onkologi pesakit luar Hospital Universiti Sains Malaysia telah melengkapkan soal selidik. Jawapan balas telah diperiksa untuk membina kesahihah (termasuk analisis faktor penerokaan untuk memeriksa struktur faktor bagi skala tersebut) dan kebolehpercayaan dalaman. Dua puluh perkara dalam skala FAMCARE adalah bergantung kepada paksi utama pemfaktoran (PAF) menggunakan SPSS, bermula dengan menilai kesesuaian data untuk analisis faktor. Matrik perkaitan menunjukkan kewujudan banyak pekali bernilai 0.3 dan ke atas. Nilai Kaiser-Mayen-Olkin ialah 0.79 dan ujian Barlett untuk kebulatan ialah sangat signifikan (p<0.001). PAF menunjukkan kewujudan empat komponen dengan nilai eigen melebihi 1, ini menjelaskan 60.8% daripada varians kumulatif. Item yang dimuatkan dalam empat domain menunjukkan perkaitan antara-faktor yang memuaskan. Secara keseluruhannya, soal selidik FAMCARE umum didapati memiliki kebolehpercayaan dalaman yang tinggi (Cronbach's α = 0.93). Skala FAMCARE versi Bahasa Melayu didapati sebagai sahih dan alat yang boleh dipercayai untuk menilai kepuasan penjaga tidak rasmi dalam tetapan pesakit luar, walaupun adalah lebih baik untuk menghapuskan item lemah yang memiliki faktor pemuatan yang rendah.

Kata kunci: Kebolehpercayaan; kepuasan penjaga; kesahihan binaan; penjaga tidak rasmi

INTRODUCTION

The National Cancer Council of Malaysia (MAKNA) is concerned about the number of cancer cases in the country which is increasing by 20000 patients every year. MAKNA has spent more than 180 million (Ringgit Malaysia) since 1994 to raise the cancer awareness and provide advice to patients (Bernama 2012). In many cancer support systems, the emphasis and focus has always been on patients and seen from their perspective (Fawzy et al. 1990; Rutten et al. 2005), although the data suggests that informal caregivers

have an equally important role in improving the quality of care amongst cancer patients.

While it is understood that informal caregivers play a strong supportive role (Grunfeld et al. 2004), it is often overlooked that they also require a strong support system to ensure their own well - being which then translates into better outcomes for those under their care. Evidence suggests that informal caregivers often have limited resources to prepare and support them in this role (Given et al. 2008; Wiles 2003); . Furthermore, informal caregivers of patients with chronic diseases such as cancer, often experience psychological crises which may lead to despair, helplessness and fragmentation of families (Grant et al. 2004; Nijboer et al. 1999; Winn et al. 2007). These issues will often lead to a negative impact on the quality of life of the patients as well as the informal caregivers themselves. Thus, it is important to identify and assess the needs of these informal caregivers.

The FAMCARE Scale has been successfully used in North America, Australia and Europe to measure the degree of family satisfaction with care of patients with advanced cancer (Aspinal et al. 2003; Bensink et al. 2007; Dean & McClement 2002). Although originally developed for use on inpatients, FAMCARE has also been used in many other different settings including outpatient cancer clinics (Follwell et al. 2009).The authors of this study realize that in the context of the Malay language-speaking community in Malaysia, informal caregivers play a major supportive role within the health care system. However, there are few studies that have evaluated that role especially from the perspective of the caregivers themselves (Hunt 2004). More research is needed into the management of symptoms, identification of caregivers satisfaction and assessment of the effectiveness of interventions to ensure continuity of care outside the clinical setting (Fakhoury et al. 1996; Lee et al. 2001). In Malaysia, one major reason for this lack of data is the unavailability of a suitable culturally relevant Malay language-based tool that informal caregivers can understand and use. Therefore, we have analyzed the validity and internal consistency of a Malay language version of the FAMCARE scale, as a first step in the assessment of needs from the caregiver's perspective. In this current study, Malaysian informal caregivers were asked to complete the Malay-language version of the FAMCARE scale in the outpatient oncology clinic of Universiti Sains Malaysia where their scores were used to describe the reliability and validity of the scale in an outpatient setting.

METHOD

STUDY DESIGN

The FAMCARE Scale has shown internal consistency and criterion related validity when it is used to evaluate family member satisfaction with cancer related care in outpatients units (Can et al. 2011; Lo et al. 2009)**.** This study was designed to evaluate the validity and internal consistency of FAMCARE when it is used to measure Malaysian informal caregiver satisfaction in outpatient oncology setting.

The study was conducted with the approval of the School of Health Sciences research committee and the Human Ethics Committee of Universiti Sains Malaysia. Informed consent was also obtained from each respondent. Participation in this study was fully voluntary and patients were aware that the study did not in any way affect any aspect of their treatment. All the data shown here were collected in February 2012 as part of an existing community-based training programme for informal caregivers. Project facilitators were trained to recruit the caregivers and interview them for the purpose of data collection.

STUDY SETTING AND PARTICIPANTS

The study was conducted among informal caregivers of cancer patients who sought medical treatment in the outpatient oncology clinic of at Hospital Universiti Sains Malaysia. The outpatient oncology clinic is run by a core team of one senior nurse, fifteen registered staff nurses, seven licensed practical nurses and seven medical doctors (MD). It has 8 beds for the daycare management of outpatient cancer patients and in 2010 the clinic catered to 654 newly diagnosed cancer cases.

TRANSLATION OF THE FAMCARE SCALE

The FAMCARE Scale (FAMCARE) is a self-report scale assessing patients/caregivers satisfaction with outpatient palliative oncology care. FAMCARE is composed of 20 items rated on a score ranging from 1 (very dissatisfied) to 5 (very satisfied). The items are not specific for a particular tumour type or symptom, but are broadly relevant for outpatients with advanced cancer. The instrument had four subscales that included: information giving (5 items), availability of care (4 items), physical care (7 items) and psychosocial care (4 items). The instrument has a mean data collection time of 22 min (Manaf & Nooi 2007) where the summed items produce a single satisfaction score (Kristjanson 1993; Manaf & Nooi 2007).

Two Malay translations of the original English version of the FAMCARE Scale were performed by two independent bilingual professional translators. The Malay versions were subsequently back-translated and compared to the original English version to ensure that the translation mirrored the original FAMCARE scale. At this point, a single translated Malay version was approved in terms of format and content.

STATISTICAL ANALYSIS

Descriptive data analysis included mean values and standard deviation for continuous variables and percentages for categorical variables used to characterize the informal caregiver responses. The statistical analysis was performed by the use of Statistical Package for Social Science SPSS version 18. Internal consistency of the responses was

estimated by using Cronbach's alpha correlation coefficient. Internal consistency is considered good if Cronbach's alpha approximates 0.70. Construct validity and dimensionality of the score was assessed by principal axis factoring, which explored factor loading and correlations between factors and individual items. This study utilized the Promax method with Kaiser Normalization to rotate the initial factor and determine the commonalities. Factor loadings were examined and the items were assigned to a subscale, following which, each subscale was compared with the subscales determined by Kristjanson (1993).

RESPONDENTS CHARACTERISTICS

Fifty Malaysian informal caregivers of cancer patients who met the criteria were included in this study. The compliance rate was high, although there were some missing answers. In all, 45 questionnaires were used for the analysis of validity and reliability for this study.

Most of the respondents were Malay, female, married and aged between 18 to 75 years with a mean age of 41.8 years. Of the 50 respondents, 17 (34%) were spouses/ partners of the patients, 10 (20%) were parents, 15 (30%) were children and 1 (2%) was a friend. Another 7 (14%) identified their relationship with the patient as 'other' without providing further clarification. A majority of the caregivers were not the sole providers of care but delivered it on a shared basis (72 %). Most of the caregivers (86%), were staying with the recipients and 22 (44%), were unemployed. In addition 24 (48%) of the informal caregivers completed their education at the secondary school level (Table 1).

TABLE 1. Demographic data

Characteristics of data	*n*	%
Ethnicity		
• Malay	46	92
• Chinese	3	6
• Indian	0	0
• Others	1	2
Gender		
• Male	16	32
• Female	34	68
Religion		
• Islam	46	92
• Christian	3	6
• Buddhist	1	2
Marital status		
• Married	35	70
• Single	13	26
• Divorced	0	0
• Widowed	1	2
• Missing data	1	2
Education level		
• No formal education	1	2
• Primary school	8	16
• Secondary school	24	48
• University-college	14	28
• Others	2	4
• Missing data	1	2
Job		
• Full time	16	32
• Part time	8	16
• Jobless	22	44
• Retired	4	8
Relationship with recipients		
• Spouse- partner	17	34
• Parents	10	20
• Children	15	30
• Friends	1	2
• others	7	14
Living arrangement		
• With the recipients	43	86
• Separately	7	14
Care status		
• Shared	36	72
• unshared	13	26

INTERNAL CONSISTENCY

The overall Cronbach's alpha correlation coefficient for the total score had solid internal reliability of 0.93. The internal consistencies at the subscales level ranged between 0.81 and 0.90.

FACTOR ANALYSIS

The sample was adequate as indicated by the Kaiser-Meyer-Olkin (KMO) value of 0.79 and Bartlett's test of sphericity being significant (p-value < 0.001). Table 2 shows the total number of components that were extracted using PAF with rotation method of Promax: the extraction was forced into 4 factors. The factor analysis shows that all 19 items loaded in the 4 components had a factor loading of more than 0.5. The total variance explained by these 4 factors was 60.8 % which is an acceptable level. These findings show that the final 19 items of scale had a good construct. These 19 items were thus allowed to remain within the Malay version of the FAMCARE scale.

Table 2 shows the factor loadings and commonalities. The factor analysis showed one very strong factor with an eigenvalue of 44.36 and more than three factors with eigenvalues of 8.60, 7.70 and 7.20. The rotated solution showed four factor loadings (Table 2).It is clear from Table 2 that seven items loaded onto factor 1 (items 16,10, 15,8, 12, 9, 17) factor 2 (items 5,11, 6,13,7,4,14) factor 3 (items 20,18.19) and factor 4 (Items 3, 2). Items number 16, 9, 13 and 5 were loaded in more than one factor with a slight difference in loading factor results. Item number 1 which is 'The patient's pain relief' had a particularly very low factor loading and low correlations with the rest of the items.

DISCUSSION

The literature indicates that patient satisfaction studies should express the patients 'feelings regarding the

TABLE 2. Factor analysis of FAMCARE scale

Item number and description	F"	F1	F2	F3	F4
16. Maklumat yang diberikan mengenai cara mengendalikan kesakitan pesakit	0.89	0.86		0.61	
10. Cara ujian dan rawatan yang dijalankan	0.76	0.83			
15. Kaedah keluarga dilibatkan dalam keputusan perawatan dan penjagaan	0.87	0.83			0.67
8. Kecepatan simptom dirawat	0.78	0.75			
12. Ketersediaan jururawat kepada keluarga	0.63	0.70			
9. Perhatian doktor kepada penerangan simptom oleh pesakit	0.69	0.67	0.66		
17. Maklumat yang diberi tentang ujian pesakit	0.70	0.64			
5. Rujukan kepada pakar perubatan	0.83		0.87	0.69	
11. Ketersediaan doktor kepada keluarga	0.76		0.72		
6. Ketersediaan katil hospital	0.77		0.70		
13. Koordinasi penjagaan	0.85		0.67		0.65
7. Perbincangan keluarga yang diadakan untuk membincangkan penyakit pesakit	0.63		0.67		
4. Maklumat yang diberi mengenai kesan-kesan sampingan	0.63		0.62		
14. Masa yang diperlukan untuk membuat diagnosis	0.68				
1. Kelegaan sakit untuk pesakit	0.51	.312			
20. Ketersediaan doktor kepada pesakit	0.88			0.86	
18. Sejauh mana ketelitian doktor memeriksa simptom pesakit	0.88			0.86	
19. Cara doktor membuat rawatan susulan ujian dan perawatan	0.74			0.75	
3. Jawapan daripada ahli profesional kesihatan	0.78				0.79
2. Maklumat yang diberi tentang prognosis pesakit	0.76				0.78
Eigenvalues, initial		8.87	1.72	1.54	1.44
Eigenvalues, rotation		8.51	1.36	1.17	1.09
Percentage of total variance		42.57	49.40	55.27	60.80

All data were derived from results shown for the 45 respondents and 20 items shown in Table 2. The extraction method was principal axis factoring with Kaiser criterion and Promax rotation. High factor loadings (.0.60) are shown in bold. F indicates commonalities of factor in the initial (unrotated) solution. F1, F2, F3, and F4 are factor loadings for the rotated solution

care they receive. Such studies should also take into consideration that patient expectations of care received in public hospitals are often lower than that which they receive within the private health care system (Beattie et al. 2002). Indeed, patient satisfaction and perception of care appear to be important factors in relation to health care outcomes. Thus, there is a need to develop valid and reliable measurements of satisfaction amongst patients. Such measurements of patient satisfaction are important in the context of the Malaysian healthcare system as well. However, a major stumbling block is the availability of instruments suitable for the assessment of patient satisfaction especially in the context of the outpatient setting (Rodriguez et al. 2010; Steele et al. 2002). Thus the translation and validation of the FAMCARE Scale represents an important step in the assessment of patient satisfaction and ultimately of the quality of health care in the Malaysian context.

A comparison of subscales identified by Kristjanson (1993), (which are information giving, availability of care, physical care, and psychosocial care) with current study subscales indicated that, the first loading factor, information giving, contained items from the physical care, psychosocial care and availability of care subscales (Table 2). The second loading factor, availability of care, contained items from the information giving, physical care, and psychosocial care subscales. Similarly, the third loading factor, physical care, contained items from the availability of care subscale. Finally the fourth factor, psychosocial care was transformed into the information giving scale. These results were consistent with those obtained from another study of validation of FAMCARE Scale in a long-term care setting (Rodriguez et al. 2010).

The results of this study showed high internal consistency and coefficient correlation for the translated FAMCARE scale as applied in the outpatient oncology clinic.

However, the analysis indicated the unidimensionality of the scale in this study population and found a wide gap between eigenvalues of the first factor and all other factors. However, item number one had low factor loading which made it preferable for that particular item to be eliminated from the scale.

This study has some limitations such as a small sample size within a population where the majority of the respondents are Malay. However, this may not necessarily limit the generalizability of this study given that there is a large Malay-speaking population in Malaysia and Indonesia. Nevertheless, further studies need to be carried out not only to determine the stability of the scale over time but also to revalidate the scale with a larger sample size.

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