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The FAMCARE-Patient scale: Measuring satisfaction with care of outpatients with advanced cancer

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ABSTRACT

Objective: To provide confirmatory results concerning the psychometric properties of a measure of satisfaction with oncology care for use with advanced stage cancer patients, and test its sensitivity to change.

Methods: We analysed data from 315 outpatients with advanced cancer participating in a randomised controlled trial of early palliative care intervention versus routine oncology care, and their caregivers. Patients completed a 16-item measure of patient satisfaction (FAMCARE-P16), based on the FAMCARE measure of family satisfaction with cancer care, and measures assessing interactions with healthcare providers, performance status and symptom burden. Caregivers completed the original FAMCARE measure. We used confirmatory factor analysis to test the patient satisfaction measure for a single-factor structure. To determine construct validity, we assessed correlations between patient satisfaction and the other patient and caregiver measures. To assess responsiveness to change, we repeated paired *t*-test analyses on the 13-item and 16-item scales for 150 patients participating in a phase II trial of palliative care effectiveness, in which the FAMCARE-P was measured at baseline, 1-week and 1-month after an outpatient palliative care intervention.

Results: A reduced 13-item version of our measure (FAMCARE-P13) possessed a one-factor structure with high reliability. Patient satisfaction was correlated in predicted directions with physical distress, communication and relationship with healthcare providers, and caregiver satisfaction. There were statistically significant increases in patient satisfaction at 1 week ($p < 0.0001$) and 1 month ($p < 0.001$).

Conclusions: We recommend the use of the FAMCARE-P13 to assess satisfaction with outpatient palliative care interventions of patients with advanced stage cancer.

1. Introduction

Effectiveness of oncology care has traditionally been measured in terms of biomedical outcomes, such as survival and disease-free survival. However, the importance of patient and family-reported outcomes for clinical trials in oncology is increasingly acknowledged, and such outcomes are increasingly incorporated into cancer clinical trials.[1,2] Subjective

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outcomes are particularly important in the palliative setting, where the focus is explicitly on quality of life for the patient and family.[3]

In studies assessing the effectiveness of palliative care interventions, relevant patient outcomes include symptom control, quality of life, quality of death and satisfaction with care.[4–7] The most consistent improvement has been shown for satisfaction with care,[6] which is a distinct concept encompassing symptom management, emotional support, communication, accessibility and coordination of care, and support of patients' decision-making.[5] However, a hindrance in the assessment of satisfaction with palliative cancer care has been the lack of measures that are validated specifically for patients with advanced cancer.[8]

In a previous study,[9] we explored the psychometrics of the FAMCARE-Patient (FAMCARE-P) scale, a measure of patient satisfaction that we constructed based on the 20-item FAMCARE measure for family satisfaction with care.[10] We selectively modified the FAMCARE items for patient use, and found that 16 items formed a scale with a single-factor structure and high internal reliability. The FAMCARE-P was used in a phase II trial of an outpatient palliative care clinic intervention, and was responsive to change, demonstrating a significant improvement in patient satisfaction at both 1 week and 1 month.[11]

The purpose of the current study was to take a confirmatory approach towards assessing the factor structure of the FAMCARE-P, and to examine in detail its construct validity in a sample of outpatients with advanced cancer and their primary caregivers. We hypothesised that the FAMCARE-P would: (1) show a single-factor structure; (2) correlate negatively with measures of symptom burden and functional disability; (3) correlate positively with measures assessing the quality of communication and quality of relationships with healthcare providers; and (4) correlate positively with caregiver satisfaction with oncology care.

2. Patients and methods

2.1. *Participants and procedure*

The sample for this study comprised patients with advanced cancer and their primary caregivers participating in an ongoing cluster randomised controlled trial of early palliative care intervention versus routine oncology care. Patients with advanced cancer were recruited from 24 outpatient oncology clinics at Princess Margaret Hospital, Toronto, and randomised either to immediate consultation and follow-up by a palliative care team, or to conventional cancer care. Inclusion criteria were metastatic gastrointestinal, genitourinary, breast, lung or gynaecological cancer (for lung cancer, Stages IIIA and B were included), age $\geqslant 18$ years, Eastern Cooperative Oncology Group (ECOG) performance status from 0 to 2, and a prognosis of 6 months to 2 years (estimated by the primary oncologist). Patients with metastatic breast or prostate cancer were also refractory to hormonal therapy; patients with locally advanced pancreatic cancer were included. Exclusion criteria were insufficient English literacy to complete the questionnaires, and inability to pass the cognitive screening test (Short Orientation-Memory-Concentration Test (SOMC) score <20 or >10 errors).[12]

Approval for this study was granted by the University Health Network Research Ethics Board. Patients completed measures of quality of life, symptom burden and satisfaction with care monthly for 4 months. Primary caregivers of consenting patients were also approached for participation, and were asked to complete measures of their own quality of life and satisfaction with the patient's care. Between 1st December 2006 and 30th April 2009, 678 patients were approached, 465 consented to participate and 331 completed baseline questionnaires. During the same time interval, 262 caregivers were approached, 209 consented and 140 completed baseline questionnaires.

2.2. *Patient measures*

The 16-item measure of patient satisfaction (FAMCARE-P16) is a self-report scale assessing patient satisfaction with outpatient palliative oncology care, which is composed of 16 items rated 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 summed items produce a single satisfaction score. A preliminary analysis indicated that the measure had good psychometric properties when used with advanced cancer patients in an outpatient palliative care clinic.[9]

The Edmonton Symptom Assessment System (ESAS) is a validated, self-administered tool to measure the severity of common symptoms in patients with advanced illness.[13] The numerical scale ranges from 0 (best) to 10 (worst), and assesses 9 main symptoms (pain, fatigue, drowsiness, nausea, anxiety, depression, appetite, dyspnoea and sense of well-being) and one 'other' symptom.[4] We replaced the 'other' symptom by two items rating insomnia and constipation, which were graded using the same 0–10 scale. Because no time window is stipulated on the ESAS form, we added instructions that symptoms were to be rated based on the previous 24-h period.[11] The ESAS Distress Score (EDS) is the prorated sum of the nine main symptom ratings.

The Communication with Health Care Providers (CARES) Medical Interaction Subscale is an 11-item subscale derived from the Cancer Rehabilitation Evaluation System.[14] It assesses whether or not patients experience problems in their interactions with their nurses and doctors, including problems related to seeking information and participating actively in medical care.

The QUAL-E Healthcare is a 26-item validated self-report measure of quality of life at the end of life, with items in four domains: life completion, symptoms impact, relationship with health provider and preparation for end of life.[15] We used the 5-item relationship with healthcare provider subscale, which assesses the degree to which individuals feel that they have access to information and can participate in treatment decisions.

The Eastern Cooperative Oncology Group (ECOG) scale is a 6-point measure ranging between 5 (dead) and 0 (fully active) that assesses the patient's ability for self-care and level of ambulation.[16]

2.3. *Caregiver measures*

Caregivers were asked to fill out 19 items from the original 20-item FAMCARE scale[10] to assess their satisfaction with oncology care. We dropped the item 'time required to make a diagnosis' because Ringdal and colleagues found this item to be poorly associated with the other FAMCARE items in their validation study.[17] We refer to this measure as the FAMCARE-C19.

2.4. *Statistical analyses*

We conducted our analysis of the baseline measures in SAS 9.1 (SAS Institute, Cary, NC). Individuals with more than 25% missing items on the FAMCARE-P16 were removed from analysis, leaving a final sample of 315 participants. Missing values were multiply imputed by the Markov Chain Monte Carlo method with PROC MI.[18] We only report the results from a single imputation because the pattern of results was the same across multiple imputations. The findings did not change substantively when analysing patients with only complete data. Satisfaction scores were calculated for 136 of the 140 caregivers (4 were excluded due to greater than 50% missing items).

A confirmatory factor analysis (CFA) was used to test for the presence of a single factor in the FAMCARE-P16. The fit of a single-factor structure to the data was evaluated using goodness of fit indices. A good fit is indicated by a Comparative Fit Index (CFI) greater than 0.95, a Non-Normed Fit Index (NNFI) greater than 0.95, and a Root Mean Square Error of Approximation (RMSEA) less than 0.06. An acceptable fit is indicated by CFI and NNFI between 0.90 and 0.95, and RMSEA between 0.06 and 0.10.[19] When there was poor fit, modification indices were consulted and items displaying problematic local dependencies were identified.[20,21] Selected items were dropped or allowed to have correlated error terms. This produced a 13-item scale, which was re-tested for a one-factor structure using CFA. Summed patient satisfaction scores were computed for the 13-item and 16-item scales, and correlations were calculated with measures of performance status, symptom burden, communication and relationship with healthcare providers, and caregiver satisfaction.

To assess the responsiveness of the scale to change, we re-examined data from the phase II trial of palliative care effectiveness[11] in which the FAMCARE-P had been measured on three occasions: at baseline, and at 1 week and 1 month after an outpatient palliative care intervention. We repeated our paired *t*-test analyses and reported on the changes in the 13-item scale and the 16-item scale from baseline to 1 week and from baseline to 1 month.

3. Results

Table 1 reports the characteristics of the patient and caregiver samples. The CFA indicated that a one-factor structure had a poor fit to the FAMCARE-P16, with CFI = 0.88, NNFI = 0.86 and RMSEA = 0.11, despite all items having significant loadings on the common factor. Modification indices revealed that the lack of fit was attributable to certain items having correlated error terms; that is, certain pairs or clusters of items continued to exhibit associations with each other, beyond what could be accounted for by an overall common factor, and yet these associations were not strong enough to produce separate factors. Such local item dependencies can occur when pairs or groups of items are highly similar in content, target or topic.[21]

Table 1 – Patient (*N* = 315) and caregiver (*N* = 136) characteristics.

Variable	Mean (SD)	Min–max
Patients		
Age	60 (12)	28–88
Female, *N* (%)	176 (56)	
Married/common-law, *N* (%)	226 (72)	
Disease site, *N* (%)		
Gastrointestinal	89 (28)	
Lung	61 (19)	
Genitourinary	61 (19)	
Gynaecological	53 (17)	
Breast	51 (16)	
ECOG	0.75 (0.57)	0–2
EDS	25 (16)	0–78
CARES	0.33 (0.45)	0–3
QUAL-E healthcare	18 (4.1)	4–25
FAMCARE-P16	67 (9.5)	25–80
FAMCARE-P13	54 (7.7)	19–65
Caregivers		
Age	56 (11)	25–83
Female gender, *N* (%)	87 (64)	
Spouse/partner of patient, *N* (%)	113 (83)	
FAMCARE-C19	78 (13)	26–95

We examined the ten most problematic item pairs. Item 15 (coordination of care) and item 16 (the availability of doctors to your family) exhibited multiple dependencies with other items, and were excluded from further analysis. However, the three most problematic item pairs remained unaddressed. Item 1 (doctor's attention to your description of symptoms) and item 2 (how thoroughly the doctor assesses your symptoms) were overly redundant. Item 1 was dropped because the thoroughness of the doctor's symptom assessment subsumes the issue of the doctor's attending to the description of symptoms. Item-pair 3 (information given about how to manage pain) and 4 (information given about side effects) was also problematic, as was item-pair 9 (information provided about your prognosis) and 10 (answers from health professionals), but it was unclear which item in each pair should be dropped. We therefore kept these items and specified correlated error terms within each pair. With these changes, a one-factor model had acceptable fit to the remaining 13 items, CFI = 0.95, NNFI = 0.94, RMSEA = 0.076. Table 2 presents the standardised factor weights for each item. We refer to this reduced scale as the 13-item version of our measure (FAMCARE-P13) (see Appendix). Internal reliabilities for the 16-item and 13-item scales were high, with Cronbach's alpha 0.94 and 0.93, respectively.

We calculated summed scores for the FAMCARE-P16 and FAMCARE-P13, and correlated them with the ECOG, EDS, individual ESAS items, CARES Medical Interaction subscale,

Table 2 – Standardised factor weights for the items of the FAMCARE-P13.

Item	Weight
2. How thoroughly the doctor assesses your symptoms	0.81
3. Information given about how to manage pain	0.67
4. Information given about side effects	0.64
5. Speed with which symptoms are treated	0.69
6. Information given about your tests	0.69
7. The way tests and treatments are performed	0.55
8. The way tests and treatments are followed up by the doctor	0.78
9. Information provided about your prognosis	0.69
10. Answers from health professionals	0.85
11. Referrals to specialists	0.66
12. The availability of doctors to answer your questions	0.81
13. The availability of nurses to answer your questions	0.66
14. The way the family is included in treatment and care decisions	0.66

Note: Items 1 (doctor's attention to your description of symptoms), 15 (coordination of care) and 16 (the availability of doctors to your family) were dropped from the 13-item reduced scale. Error terms for items 3 and 4 were correlated at 0.29. Error terms for items 9 and 10 were correlated at 0.24.

QUAL-E relationship with healthcare provider subscale, and FAMCARE-C19 (see Table 3). All correlations were significant and in the predicted directions. Greater patient satisfaction was associated with higher performance status, lower symptom burden (especially anxiety and well-being), greater caregiver satisfaction with oncology care, and better communication and relationship with healthcare providers. Finally, we identified patients scoring ⩾64 on the FAMCARE-P16 as generally satisfied, because this cut-off value is associated with rating 4 (satisfied) on all 16 items: 62% of patients were categorised as generally satisfied. We similarly identified patients scoring ⩾52 on the FAMCARE-P13 as generally satisfied: 63% were categorised as generally satisfied.

Table 3 – Correlations with the FAMCARE-P16 and FAMCARE-P13 scales.

	FAMCARE-P16	FAMCARE-P13
ECOG	−0.14*	−0.15*
EDS	−0.34**	−0.36**
Individual ESAS items		
Pain	−0.16*	−0.17*
Fatigue	−0.25**	−0.25**
Nausea	−0.17*	−0.18*
Depression	−0.25**	−0.25**
Anxiety	−0.31**	−0.32**
Drowsiness	−0.24**	−0.24**
Appetite	−0.23**	−0.24**
Well-being	−0.33**	−0.34**
Dyspnoea	−0.16*	−0.18*
Constipation	−0.12*	−0.12*
Insomnia	−0.12*	−0.13*
CARES Medical Interaction	−0.49**	−0.50**
QUAL-E relationship with healthcare provider	0.55**	0.55**
FAMCARE-C19	0.55**	0.54**

Note: Correlations with the FAMCARE-C19 were based on data from the 136 caregiver and patient pairs. All other correlations were based on data from the 315 patients.

* $p < .05$

** $p < .001$.

To assess the responsiveness of the 13-item scale to change, we reanalysed the data from our phase II trial of palliative care effectiveness.[11] Relative to baseline, we found statistically significant increases in the 13-item scale at 1 week, $M = 4.4$, confidence interval $(\mathrm{CI})_{.95}$ (2.5, 6.3), $p < 0.0001$, and at 1 month, $M = 3.6$, $\mathrm{CI}_{.95}$ (1.5, 5.8), $p = .0009$. We also found significant increases in the 16-item scale at 1 week, $M = 5.7$, $\mathrm{CI}_{.95}$ (3.4, 8.0), $p < 0.0001$, and at 1 month, $M = 4.7$, $\mathrm{CI}_{.95}$ (2.1, 7.2), $p = 0.0004$.

4. Discussion

This study was a confirmatory analysis of the factor structure and validity of a new measure of patient satisfaction in a sample of outpatients with advanced cancer. We examined the functioning of the FAMCARE-P and found that a reduced 13-item version fit the hypothesised one-factor model. Both the 13-item and 16-item scales were associated in hypothesised directions with related constructs, including symptom severity, satisfaction with communication, caregiver satisfaction and patient quality of life as determined by the relationship with healthcare providers. We recommend the use of the 13-item scale (see Appendix) due to its brevity and stronger one-factor structure; however, both scales are appropriate in clinical and research settings to measure the effectiveness of outpatient oncology palliative care.

The present study revealed stronger relationships between patient satisfaction and symptom burden, and between patient satisfaction and functional disability than our initial exploratory study of the FAMCARE-P16 in patients with advanced cancer.[9] This may partly be due to the fact that the sample size for the current study was more than twice the size of that in the preliminary study. It is also noteworthy that patients in the present study had less advanced disease than patients in the earlier study. In another study measuring satisfaction with care in medical inpatients at the end of life, it was similarly found that satisfaction was not related to depression or anxiety and only weakly associated with symptom severity.[22] When patients with advanced cancer are being treated relatively early in the disease course, their satisfaction with care may depend more on the effectiveness of treatment to reduce physical distress. However, when such patients are treated later in the disease trajectory, when progressive physical deterioration can be expected, individuals may begin to evaluate their quality of care based less on their actual physical health.

It is important to distinguish satisfaction with care from related constructs of quality of life, quality of death and quality of care. Quality of life is measured subjectively, and includes the domains of physical, psychological, social and functional well-being. In palliative care, spiritual and existential well-being has been described as an additional domain of importance.[23,24] Quality of death is generally measured by the family member after the death of the patient, and encompasses physical, psychological, social and spiritual experiences; the nature of health care, life closure and death preparation; and the circumstances of death.[7] Satisfaction with care assesses the fulfilment of individual needs and expectations of those receiving care by means of indirect or direct questions about the quality of care provided.[25] Quality of care includes not only the aspects of care relevant at the individual level, but also concepts such as equity, which are important at the societal level.[26] For this reason and for others, such as individual differences in perception of satisfaction and reluctance of patients to criticise health care providers, satisfaction with care is an incomplete indicator of the quality of care of a particular health service. Nonetheless, it is an important measure of whether a particular service meets the needs and expectations of patients and/or families under its care.

Validated measures exist to measure quality of life for patients with cancer[27,28] including in palliative care,[15,29] and for measuring quality of death[30] but these are not appropriate for directly measuring satisfaction with care. A measure has also been developed to measure quality of care at the end of life.[31] However quality of care is not defined in this paper, and the measure includes items such as 'Have you a close relationship with your family?', 'Have you spent a lot of time with your family?', 'Have you felt that you life is meaningful and valuable' and 'Have you been dealing well with finishing touch on your life?', which are similar to items usually used for quality of life measures, and do not link quality of life specifically to care from the medical team.

Although there are existing measures of satisfaction with oncology care, none are specific for patients in the palliative care outpatient setting. Some validated measures of satisfaction with palliative care are designed for use by family members rather than by patients.[10,32] The QUEST (Quality of End-of-life care and satisfaction with treatment scale) measures patient satisfaction with care by physicians and nurses, but was designed and validated specifically for inpatients at the end of life.[22] Several scales measure patient satisfaction with outpatient oncology care, but one refers only to care as it relates to treatment by physicians,[33] one is very long, with 60 items in total,[34] one is intended to evaluate patients' experiences when taking anticancer therapy,[35] and none are specifically for patients in palliative outpatient settings.[33–35] In a recent systematic review of studies assessing satisfaction with care at the end of life,[5] only one study used a measure designed for the end of life, which was a retrospective measure of family satisfaction with care (an item from the Toolkit Afterdeath Survey).[36] Thus the FAMCARE-P provides a measure for outpatient oncology palliative care, which was previously not available.

A limitation of our study is that this scale was developed from a previously existing scale that was designed for retrospective use by family members after the death of the patient, rather than from direct interviews with patients. However the FAMCARE has face value for use prospectively and with patients, and has been used previously in this way.[37–39] Our finding that the scale is sensitive to change after care provided by a palliative care team indicates that it is useful for assessing patient satisfaction in trials of palliative care interventions. As previously noted, Ringdal and colleagues found that the one FAMCARE item assessing satisfaction with the time required to make a diagnosis did not relate well to other FAMCARE items,[17] and this item was removed when we constructed the initial FAMCARE-P16 scale. This omission is perhaps appropriate from a clinical perspective, in that interventions by the current clinical team are unlikely to change satisfaction with diagnostic issues that occurred earlier in the cancer trajectory. Issues of communication of diagnosis and prognosis are nonetheless important, and there is an existing measure that specifically assesses satisfaction with care and communication at the time of the diagnosis of advanced cancer and initiation of cancer-directed treatment.[40]

In conclusion, we have developed and validated a brief measure of patient satisfaction. This instrument may be useful to oncology clinicians, researchers and other health professionals seeking to evaluate quality of care in settings where patients have advanced and progressive disease. Because the FAMCARE-P measure does not contain items specific to any one nation or healthcare system, it is likely relevant internationally, similar to the original FAMCARE measure.[10,17,37] Due to its responsiveness to change, it may be particularly useful for clinical trials assessing satisfaction with oncology palliative care.

Conflict of interest statement

None declared.

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Appendix. The 13-item FAMCARE-Patient scale (FAMCARE-P13)

1 = very dissatisfied, **2** = dissatisfied, **3** = undecided, **4** = satisfied, **5** = very satisfied.

How satisfied are you with:

1. How thoroughly the doctor assesses your symptoms.
2. Information given about how to manage pain.
3. The availability of nurses to answer your questions.
4. Information provided about your prognosis.
5. Speed with which symptoms are treated.
6. Information given about your tests.
7. The way tests and treatments are performed.
8. The availability of doctors to answer your questions.
9. Answers from health professionals.
10. Referrals to specialists.
11. The way tests and treatments are followed up by the doctor.
12. Information given about side effects.
13. The way the family is included in treatment and care decisions.

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