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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]