

Satisfaction with oncology care among patients with advanced cancer and their caregivers

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Abstract

Purpose Satisfaction with care is important for quality assurance in oncology, but may differ between patients and caregivers. We aimed to assess satisfaction with cancer care in paired analyses of these groups, examine differences between them, and identify areas for potential intervention. **Methods** Patients with advanced cancer and their caregivers were recruited from 24 medical oncology outpatient clinics. Satisfaction with care was measured using the FAMCARE (caregivers) and FAMCARE-Patient (patients) scales. Quality of life (QOL) was measured with the Caregiver QOL Index-Cancer (caregivers) and FACIT-Sp (patients). The paired *t* test assessed differences in overall

satisfaction and individual scores. In addition, scores were dichotomized into satisfied versus not satisfied, and McNemar's test was used to assess differences. Multivariable linear regression analyses assessed predictors of patient and caregiver satisfaction, respectively.

Results Satisfaction ratings in the 191 patient–caregiver pairs were high, but patients were more satisfied ($p = 0.02$). Both groups were least satisfied with information regarding prognosis and pain management. Caregivers were significantly less satisfied than patients regarding coordination of care ($p = 0.001$) and family inclusion in treatment/care decisions ($p < 0.0001$). In both groups, higher education was associated with lower satisfaction ($p \leq 0.01$), while better QOL predicted greater satisfaction ($p < 0.0001$).

Conclusions Communication regarding pain control and prognosis were identified as key areas for improvement. Caregivers seem to desire greater involvement in treatment decisions, though this must be balanced with patient autonomy.

Keywords Satisfaction with care · Oncology · Palliative care · Quality of life · Patient–clinician communication · Caregiver satisfaction

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Introduction

Satisfaction with medical care was first identified as an integral component of health care quality assurance programs by the World Health Organization in 1989 [1]. It has been defined as the assessment of “the fulfillment of individual needs and expectations of those receiving care by means of indirect or direct questions about the quality of care provided” [2]. In this context, the assessment of

satisfaction with care allows patients and their families to articulate their preferences and perspectives [3]. In a systematic review of satisfaction with care at the end of life, it was suggested that satisfaction with care should include accessibility, coordination and personalization of care, symptom management, communication, emotional support and support around decision making [4].

Several studies have examined factors associated with patient satisfaction in oncology settings. Among socio-demographic factors associated with greater satisfaction levels, age was most consistently identified, with older patients tending to be more satisfied [5–7]. Waiting times and time spent with the physician [8–10], continuity of care [8, 10, 11], and communication styles or interpersonal skills [9, 11–14] have also been shown to influence patient satisfaction.

The assessment of caregiver satisfaction is increasingly recognized as important in cancer care. As cancer trajectories become longer and care is delivered more in the ambulatory setting, caregivers often accompany patients to outpatient visits and are routinely called upon to provide care to patients at home [15]. Clinicians are encouraged to consider patients and their caregivers as a “unit of care” [16] and to provide support not only for patients but also for their families [17]. Caregivers often consider themselves advocates for patients, who may feel reluctant to express dissatisfaction with their care team [18, 19]. Feeling involved in clinic visits has been associated with increased caregiver satisfaction [20, 21] and with fewer unmet needs across multiple domains (information, psychological and patient care) [21, 22]. Elsewhere, caregivers have reported being least satisfied with information provision and family support [23].

Direct comparison of satisfaction scores of patients and their caregivers is important to identify unmet needs of the patients versus their caregivers and to uncover how these needs may differ or interact [22]. To our knowledge, no study to date has directly compared patient and caregiver reports of satisfaction with oncology care. A small number of studies have documented satisfaction of patients and their caregivers simultaneously, but none of these utilized matched pairs completing the same measure, and results were reported either for one group alone [10] or presented caregiver and patients results independently, with caregivers tending to report lower satisfaction scores than patients [23, 24]. One study [25] suggested that spouses reported greater congruence in satisfaction scores with their ill partners than did non-spouses caregivers, and another that female and older caregivers were more satisfied [26], but these findings have not been replicated.

The purpose of the current study was to assess satisfaction with care in patients with advanced cancer and their caregivers in an ambulatory oncology setting and to examine whether there were important differences between

patient and caregiver reports. Secondary aims were to identify factors associated with patient and caregiver satisfaction with care. We hypothesized that caregivers would report less satisfaction with care than the patients they cared for, particularly for items relating to family support.

Methods

Participant selection and study procedures

Patients and their caregivers were recruited from 24 medical oncology outpatient clinics at Princess Margaret Cancer Center, a comprehensive cancer center in Toronto, Canada, between December 2006 and September 2010. Participants were recruited for a cluster randomized controlled trial, comparing early intervention by a specialist palliative care team with conventional oncology care, in patients with advanced cancer [27].

Patients were eligible if they had a diagnosis of stage IV gastrointestinal, genitourinary, gynecological or breast cancer or lung cancer. Stage III lung cancer and locally advanced esophageal or pancreatic cancer were also included. We included only these sites because they are the largest solid tumor sites, and we could not feasibly recruit prospectively from all clinics in the cancer center [28]. Other eligibility criteria included a clinical prognosis of 6 months to 2 years, and an Eastern Cooperative Oncology Group (ECOG) performance status score of 0–2 [29], both of which were determined by the patient’s primary medical oncologist. Each patient was asked to identify their primary caregiver, who was subsequently approached either in person, if present, or by telephone to request study participation and to seek informed consent. Exclusion criteria for both patients and caregivers were aged less than 18 years and insufficient English to provide informed consent and complete questionnaires. In addition, patients were excluded if they had a low score on a cognitive screening tool, Short Orientation–Memory–Concentration Test (score <20 or >10 errors) [30].

All patients and caregivers provided informed consent; those who chose not to proceed with the trial were asked to provide written consent to complete baseline measures only. Patients and caregivers completed measures at baseline and monthly for 4 months. For this study, baseline data alone were used for all analyses. The study received approval from the University Health Network Research Ethics Board.

Measures

Patient and caregiver demographic details were collected at baseline; data collected included age, gender, ethnicity,

religion, level of education, marital status, living arrangement, employment status and household income. Caregivers provided additional information on their relationship to the patient. Patient medical records were reviewed by research staff to obtain additional information regarding cancer diagnosis and stage, cancer treatment status and comorbidity.

Caregiver satisfaction with care was measured using the FAMCARE scale, a 19-item self-report questionnaire that uses a five-point Likert-type scale with anchors of 1 (very dissatisfied) and 5 (very satisfied), which has been shown to have high internal consistency, test–retest reliability and mean inter-item correlation [31, 32]. It was originally developed to measure family satisfaction across 4 subscales: information giving, availability of care, psychosocial care and physical patient care in patients with advanced cancer [31] and was used as a prospective measure in several studies [22, 26, 33, 34].

Patient satisfaction with care was measured using the 16-item FAMCARE-Patient scale. This is a patient-reported scale, which was derived from the FAMCARE scale. It has been validated for use by patients (whether or not they have caregivers) and has high reliability, validity and responsiveness to change [34–36].

Patient symptom control was measured using the Edmonton Symptom Assessment System (ESAS), a validated and self-administered instrument to measure the severity of common symptoms in patients with advanced incurable illness [37]. Brief and easy to complete, it is widely used as a general symptom screening tool among oncology patients [38]. The scale assesses 9 main symptoms (pain, fatigue, drowsiness, nausea, anxiety, depression, appetite, dyspnea, sense of well-being) and ranges from 0 (best) to 10 (worst) [39]. As 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 [34]. The ESAS Distress Score (EDS) was calculated by summing the ratings on the 9 main symptoms, multiplying by 9 (the number of possible items) and dividing by the total number of items completed [39].

Caregiver quality of life was measured using the Caregiver QOL Index-Cancer (CQOLC), a 35-item multi-dimensional tool developed through in-depth interviews with caregivers of cancer patients [40]. It has been validated for use in both curative and palliative settings [41, 42]. It uses a five-point Likert-type scale to measure four elements of caregiver quality of life: physical, emotional, social family/financial and spiritual.

Patient quality of life was measured with the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp). This is a valid, reliable, 39-item measure, which includes the 27-item core Functional Assessment of Cancer Therapy-General (FACT-G) [43]

and the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp-12) [44]. This scale measures physical, social/family, emotional, functional and spiritual well-being.

Statistical analysis

Descriptive statistics were calculated for all variables. For total FAMCARE scores and individual FAMCARE items, the paired differences in satisfaction scores between patients and caregivers were compared using paired *t* tests. The results for individual FAMCARE items for both patients and caregivers were dichotomized into satisfied (scores ≥ 4) or dissatisfied (scores ≤ 3), as these differences were deemed to be most clinically significant. Difference in satisfaction between patients and caregivers for these dichotomized data was tested using McNemar's test.

Univariable and multivariable analyses were performed, using a linear regression model, to determine predictors of patient and caregiver overall satisfaction scores. Univariable analyses for patient satisfaction assessed patient sex, age, ethnicity, education level (university/college vs. other), income ($\geq \$60,000$ vs. $< \$60,000$), tumor site, relationship to caregiver (spouse vs. non-spouse), chemotherapy (yes vs. no), Eastern Cooperative Oncology Group (ECOG) performance status score, EDS, and patient and caregiver quality of life (FACIT-Sp and CQOLC). For caregivers, sex, age, ethnicity, education level, income, tumor site, relationship to patient, patient on chemotherapy (yes vs. no), patient ECOG score, patient EDS, and patient and caregiver quality of life were investigated. All outcomes for which $p < 0.25$ were included in the multivariable analyses. All analyses were performed using SAS v9.2.

Results

Caregiver and patient characteristics

Of the 1016 eligible patients approached for enrollment in the RCT, 478 identified a caregiver. One hundred and seven caregivers were not approached for the following reasons: patient refusal on behalf of the caregiver ($n = 42$); caregiver not contactable ($n = 12$); patient withdrawal before the caregiver could be approached ($n = 22$) and reason not indicated ($n = 31$). Of 371 caregivers approached, 182 consented and were enrolled in the RCT. A further nine consented to completion of baseline measures only (but not to RCT participation). Our study sample was therefore comprised of 191 caregiver–patient pairs. Patient cancer details and patient and caregiver demographics are shown in Table 1. Caregivers tended to be younger than patients (mean age 56 vs. 60), were more likely to be female (66 vs.

Table 1 Patient and caregiver demographics

Characteristic	Patients (<i>N</i> = 191)		Caregivers (<i>N</i> = 191)	
	<i>n</i>	%	<i>n</i>	%
Age				
Mean (SD)	60.3	11.4	56.1	12.1
Median (range)	61.0	28–88	57.0	22–83
Female	89	46.6	126	66.0
Married/common law	176	92.1	182	95.8
European ethnicity	162	84.8	157	82.2
Education				
College/university/other	122	63.9	123	64.4
High school or lower	67	36.1	65	36.6
Employment status				
Retired	85	44.5	68	35.6
Employed	39	20.4	95	49.7
On disability	41	21.5	4	2.1
Student	0		2	1.1
Unemployed	26	13.6	22	11.5
Income				
≤\$14,999	6	4.4	4	2.9
\$15,000–29,999	13	9.6	13	9.3
\$30,000–59,999	38	28.2	37	26.4
≥\$60,000	78	57.8	86	61.4
QOL ^a				
Mean (SD)	112.2	21.7	87.5	23.6
ECOG				
0	52	27.2		
1	124	65.9		
2	15	7.9		
Primary tumor site				
Gastrointestinal	72	37.7		
Breast	33	17.3		
Genitourinary	34	17.8		
Gynecological	21	11.0		
Lung	31	16.2		
ESAS EDS, mean (SD)	25.2	15.3		
Living with patient			171	89.5
Relationship to patient				
Spouse/partner			161	84.3
Parent			2	1.1
Son/daughter			22	11.5
Sibling			3	1.6
Other			3	1.6

^a Quality of life for patients was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp) measure for patients, and the Caregiver QOL Index-Cancer measure for caregivers

ESAS EDS Edmonton Symptom Assessment System Distress Score, ECOG Eastern Cooperative Oncology Group performance status

47 %) and were more likely to be employed at the time of the study (50 vs. 20 %). Ninety-six percent of caregivers and 92 % of patients were married or lived common law; 84 % of caregivers were the spouses of the patients they cared for and 90 % were living with the patient.

Satisfaction ratings of patients and their caregivers

Satisfaction ratings of both patients and caregivers were high, with median scores of 4 or 5 for all items in both groups. The median overall FAMCARE satisfaction score, out of a possible score range of 16–80, was 68.3 (IQR 61–75) for patients and 66 (IQR 61–75) for caregivers. Patients were more highly satisfied overall, with a mean difference in overall score of 1.63 (SD 9.36; $p = 0.02$) (Table 2).

The proportions of patients and caregivers rating that they were satisfied (scoring 4 “satisfied” or 5 “very satisfied” on the FAMCARE scale) for each common item on the FAMCARE and FAMCARE-P are shown in Table 2. Eighty-five percent or more of both patients and caregivers were satisfied with “doctor’s attention to description of symptoms,” “the way tests and treatments are performed,” “referral to specialists” and “the availability of the nurse.” Both patients and caregivers were least satisfied with “information provided about prognosis” (only 70 % of patients and 69 % of caregivers reporting satisfaction) and “information given about how to manage pain” (76 % satisfaction among patients, 70 % for caregivers).

Patients had significantly higher ratings than their caregivers both for overall satisfaction and for paired differences in scores for the following two items: “the way the family is included in treatment and care decisions” ($p < 0.0001$ for overall satisfaction and paired differences) and “coordination of care” ($p = 0.002$ for overall satisfaction; $p = 0.001$ for paired differences) (Table 2).

Factors associated with satisfaction with care

Factors associated with patient and caregiver total satisfaction scores are shown in Tables 3 (patients) and 4 (caregivers). On univariable analysis, female patient gender ($p = 0.001$) and higher patient education level ($p = 0.0007$) were associated with lower patient satisfaction with care, whereas better symptom control and patient and caregiver quality of life scores were associated with greater patient satisfaction with care (both $p < 0.0001$). On multivariable analysis, education level ($p = 0.0002$) and patient and caregiver quality of life ($p = 0.0005$ and $p = 0.04$, respectively) remained statistically significant.

Table 2 Comparison of patient and caregiver satisfaction

FAMCARE	Patient		Caregiver		Patient–Caregiver Agreement		
	<i>n</i>	Satisfied <i>N</i> (%)	<i>n</i>	Satisfied <i>N</i> (%)	Overall Satisfaction (Y/N)	Paired difference in scores	<i>p</i> value
Question					<i>p</i> value	Mean (SD)	<i>p</i> value
Total score (16 items)	189		187			1.63 (9.36)	0.02
Doctor's attention to description of symptoms	188	169 (90)	182	161 (88)	0.50	0.04 (0.85)	0.48
How thoroughly doctor assesses symptoms	187	164 (88)	186	155 (83)	0.15	0.10 (0.89)	0.11
Information given about how to manage pain	168	128 (76)	162	114 (70)	0.34	0.16 (1.07)	0.07
Information given about side effects	186	153 (82)	188	157 (84)	0.88	0.01 (0.92)	0.94
Speed with which symptoms are treated	182	149 (82)	176	135 (77)	0.29	0.12 (1.03)	0.14
Information given about tests	188	159 (80)	183	143 (78)	0.88	0.13 (1.03)	0.08
The way tests and treatments are performed	189	173 (92)	189	169 (89)	0.57	0.05 (1.00)	0.51
Follow-up on tests and treatments	187	168 (90)	184	155 (84)	0.09	0.13 (0.85)	0.04 ^a
Information provided about prognosis	188	132 (70)	188	130 (69)	0.88	0.05 (1.03)	0.52
Answers from health professionals	187	163 (87)	190	156 (82)	0.16	0.11 (0.91)	0.11
Referrals to specialists	179	158 (88)	176	154 (88)	0.70	0.07 (0.95)	0.37
Availability of doctors to answer questions	185	151 (82)	183	155 (85)	0.47	0.02 (0.90)	0.80
Availability of nurses to answer questions	183	163 (89)	175	152 (87)	0.13	0.12 (0.85)	0.07
Family inclusion in treatment/care decisions	189	176 (93)	176	144 (82)	<0.0001	0.29 (0.85)	<0.0001
Coordination of care	186	165 (89)	174	136 (78)	0.002	0.25 (0.99)	0.001
Availability of doctors to the family	179	146 (82)	175	140 (80)	0.53	0.06 (0.93)	0.40

Paired differences were assessed using the paired *t* test and agreement on overall satisfaction using McNemar's test

^a Not significant after adjusting for multiple testing

For caregivers, on univariable analysis, higher education level ($p = 0.01$) was associated with lower satisfaction; better patient symptom control ($p = 0.005$), better patient quality of life ($p = 0.005$) and better caregiver quality of life (CQOLC, $p < 0.0001$) were associated with greater satisfaction. On multivariable analysis, caregiver quality of life ($p < 0.0001$) and education level ($p = 0.01$) remained significant.

Discussion

To our knowledge, this is the first study to report paired patient–caregiver satisfaction scores in an outpatient cancer population. By comparing patient and caregiver scores using the same satisfaction measure, we were able to make comparisons on an item by item basis. Our study demonstrated high levels of overall satisfaction with care for both caregivers and patients. Caregivers were, however, less satisfied than patients, particularly regarding coordination of care and inclusion of the family in treatment and care decisions. Both patients and caregivers were least satisfied with information about prognosis and about pain control. Education beyond the high school level was associated

with lower levels of satisfaction for both patients and caregivers, whereas better quality of life for both groups predicted greater satisfaction. These results have implications for the potential improvement of outpatient oncology care.

Satisfaction items that were rated highly by both patients and caregivers were the physician's attention to symptoms, the way tests and treatments were carried out, referrals to specialists and the availability of the nurse. These items range from history taking to treatment and referral to follow-up, indicating satisfaction with a broad range of care elements. The two items that were associated with the lowest levels of satisfaction among patients and caregivers both involved information: about pain control and about prognosis. Other studies conducted in patients with advanced disease, in both cancer [45] and intensive care unit settings [46], have similarly reported less satisfaction with information-based services compared with treatment (Table 4).

General methods to improve communication of information include encouraging patients to become more actively involved in consultations by asking questions, encouraging the use of prompt sheets, developing patient-friendly information resources, providing written

Table 3 Factors associated with patient satisfaction

Predictor	Patient satisfaction			
	Univariable		Multivariable	
	Estimate (SE)	<i>p</i> value	Estimate (SE)	<i>p</i> value
Sex (patient, female vs. male)	−4.37 (1.35)	0.001	−2.47 (1.43)	0.09
Age (patient, years)	0.08 (0.06)	0.18	−0.10 (0.06)	0.10
Ethnicity (patient, Euro vs. other)	2.74 (1.91)	0.15	2.79 (1.78)	0.12
Education (patient) university/college versus other	−4.86 (1.41)	0.0007	−5.17 (1.38)	0.0002
Income (patient, ≥60 k vs. other)	−0.24 (1.73)	0.89		
Tumor site (gastrointestinal = reference)		0.62		
Breast	−2.82 (1.98)	0.16		
Genitourinary	0.40 (1.96)	0.84		
Gynecological	−1.10 (2.34)	0.64		
Lung	−0.09 (2.03)	0.97		
Relationship to patient (spouse/partner vs. other)	3.69 (1.90)	0.05	−0.40 (1.88)	0.83
Active chemo (yes vs. no)	0.91(1.58)	0.56		
ECOG	−2.14 (1.23)	0.08	1.53 (1.26)	0.22
ESAS EDS	−0.21 (0.04)	<0.0001	−0.08 (0.06)	0.18
QOL (patient)	0.19 (0.03)	<0.0001	0.15 (0.04)	0.0005
QOL (caregiver)	0.09 (0.03)	0.003	0.06 (0.03)	0.04

Multivariable analysis included all predictors with *p* value less than 0.25

QOL quality of life, ESAS EDS Edmonton Symptom Assessment System Distress Score, ECOG Eastern Cooperative Oncology Group performance status, SE standard error

Table 4 Factors associated with caregiver satisfaction

Predictor	Caregiver satisfaction			
	Univariable		Multivariable	
	Estimate (SE)	<i>p</i> value	Estimate (SE)	<i>p</i> value
Sex (caregiver, female vs. male)	0.50 (1.72)	0.77		
Age (caregiver, years)	0.12 (0.07)	0.09	−0.08 (0.08)	0.30
Ethnicity (caregiver, Euro vs. other)	3.65 (2.10)	0.08	1.87 (2.26)	0.41
Education (caregiver, university/college vs. other)	−4.21 (1.69)	0.01	−4.60 (1.77)	0.01
Income (caregiver, ≥60 k vs. other)	−0.78 (2.02)	0.70		
Tumor site (gastrointestinal = reference)		0.46		
Breast	−0.83 (2.34)	0.72		
Genitourinary	−3.06 (2.29)	0.18		
Gynecological	−4.42 (2.72)	0.11		
Lung	−2.00 (2.42)	0.41		
Relationship to patient (spouse/partner vs. other)	1.62 (2.22)	0.47		
Active chemo (yes vs. no)	0.15 (1.85)	0.94		
ECOG	−2.39 (1.44)	0.10	0.94 (1.63)	0.56
ESAS EDS	−0.15 (0.05)	0.005	−0.07 (0.07)	0.32
QOL (patient)	0.11 (0.04)	0.005	0.01 (0.05)	0.86
QOL (caregiver)	0.18 (0.03)	<0.0001	0.19 (0.04)	<0.0001

Multivariable analysis included all predictors with *p* value less than 0.25

QOL quality of life, ESAS EDS Edmonton Symptom Assessment System Distress Score, ECOG Eastern Cooperative Oncology Group performance status, SE standard error

summaries of consultations and the use of telephone help lines or support groups [47]. In addition, communication about pain control can be improved by educating patients about common opioid misconceptions, utilizing a pain diary and providing detailed instructions regarding how and when to contact the health care team [48]. For information about prognosis, a recent study has shown that providing a range of estimates (including best and worst case scenarios as well as typical life expectancies) was preferred by patients than providing median survival time alone, and that a printed summary of this information was also helpful [49]. Involvement of a palliative care team has also been found to increase overall satisfaction with care [27, 34, 50].

Our results demonstrating greater satisfaction with care in patients than in caregivers are consistent with those from other studies that have not used matched caregiver–patient pairs [23, 51]. There may be several reasons why caregivers tend to rate satisfaction less favorably than patients. Caregivers may feel less reluctant to criticize services, or to give less socially acceptable responses, than patients, who are more dependent upon these services and may fear negative consequences as a result of complaining. Caregivers may have higher expectations of services than patients, who may be more consumed with dealing with the day-to-day consequences of their illness, leading to lower levels of satisfaction among caregivers when unfulfilled [18, 19]. Caregivers may also feel their particular needs are addressed less frequently than those of patients [52], leading to lower levels of satisfaction. This is consistent with the results of our survey, in that the two items with the greatest divergence in patient and caregiver responses, namely coordination of care and inclusion of family in treatment and care decisions, both directly affect caregivers.

In our study, a higher level of education was associated with less satisfaction with care in both patients and caregivers. This association is consistent with other studies that have found similar results in different populations [14, 53]. More highly educated individuals are likely to have greater expectations regarding the care provided, which may in part explain this phenomenon [54]. Although female gender was associated with less satisfaction in univariable analyses, this relationship did not hold in multivariable analyses. This is consistent with other studies, which have also found no significant differences in satisfaction with care based on gender [5, 18, 25]. Although caregivers were generally younger than patients, age was also not significantly associated with satisfaction with care. Quality of life was a significant predictor of satisfaction with care for both patients and caregivers, which is consistent with other studies [55, 56], and affirms the close link between the two concepts [54]. Patients and caregivers with worse quality of life may have more complex physical and psychosocial

care needs that may be more difficult to meet. In our sample of ambulatory patients, performance status was quite high in the majority, which is likely why differences according to performance status were not observed.

Our study has some limitations. The study was conducted at a tertiary cancer center, where there might be greater levels of satisfaction, and the majority of respondents were of European ethnicity had high education levels, good performance status and were married or living common law. Data were collected for a randomized trial of early palliative care intervention. All of these factors may limit generalizability of findings. This is a cross-sectional study, which does not reflect any changes in satisfaction that may develop over time, [57] and causality or directionality cannot be inferred from the results of the regression analyses. Satisfaction questionnaires tend to be positively skewed, [58] and may have a ceiling effect [59]. However, the FAMCARE has been recommended as the instrument of choice for measuring satisfaction with quality of care at the end of life when compared across domains of reliability, validity, responsiveness, interpretability and burden [60], and we have demonstrated responsiveness to change of the FAMCARE-Patient measure after intervention of a palliative care team [27]. There may be areas of satisfaction or dissatisfaction unaddressed by FAMCARE; we are currently analyzing qualitative interviews of patients and caregivers, which may identify areas of satisfaction with care beyond of the scope of the FAMCARE questionnaire.

In summary, although our results reveal high levels of satisfaction with ambulatory oncology care among both patients and caregivers, there are areas for potential improvement, especially regarding communication of information regarding pain control and prognosis. From the caregiver perspective, coordination of care and family inclusion in treatment and decision making could also be improved, though this must be balanced with patient autonomy. In addition, the ability of each patient and caregiver to absorb complex health care information should be considered. More educated patients and caregivers may require additional input to appropriately meet their needs, but also could be called upon to identify areas for potential intervention. Such interventions might be at the level of the treating oncology team, or involve external consultations, such as a palliative care team. Further studies are required to assess the impact of these interventions on patient and caregiver satisfaction.

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