



# Couples' symptom burden in oncology care: perception of self and the other

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## Abstract

**Background** The literature suggests that psychological distress and quality of life are interdependent in couples coping with cancer. The current study seeks to extend these findings to physical symptom burden, examining differences in symptom self-rating and perception of partner symptoms.

**Methods** Couples were approached while waiting for an integrative oncology service. Fifty patients and their partners completed the Edmonton Symptom Assessment Scale (ESAS-FS; twelve symptoms, scores 0–10, 10 worst possible) and a Global Health measure (PROMIS10). Patient and partner each also completed the ESAS-FS as it related to their perception of the other's symptoms. ESAS distress subscales analyzed included Global (GDS), Psychosocial (PSS), and Physical (PHS). Analyses included paired *t* tests to examine all measures.

**Results** Fifty-eight percent of patients were female with most common cancer diagnoses of breast (22%), gastrointestinal (16%), and thoracic/H&N (16%). For ESAS-FS self-ratings, patients had significantly higher physical distress than partners, with a no significant difference in psychosocial distress. For PROMIS10 self-ratings, patients reported significantly lower global health and physical health, ( $p$ 's < 0.001); no differences were found for mental health between patients and caregivers. Patient rating of partner physical distress (PHS,  $p = 0.01$ ) was significantly higher than partner self-rating, with no significant difference observed in ratings for psychosocial distress. Partner rating of patient psychosocial distress (PSS,  $p < 0.001$ ) and physical distress (PHS,  $p = 0.001$ ) was significantly higher than that of patient self-rating.

**Conclusions** Our findings suggest that both patients and partners perceive physical distress of the other higher than self; however, patients may be more sensitive to psychosocial distress in their partners.

**Keywords** Couple communication · Caregiver · Symptom burden · Integrative oncology · Patient reported outcomes · Edmonton Symptom Assessment System

## Introduction

A cancer diagnosis can place a great burden on both patients and their families, in particular their spouses/partners [1–3]. While patient symptom burden and quality of life (QOL)

concerns have been substantiated in a large body of literature, caregiver burden in the context of cancer is a fairly recent area of research interest. Nevertheless, numerous studies have identified a high incidence of psychological distress, sleep disturbance, and fatigue [1].

Both populations experience a significant amount of distress that can have negative effects on their overall health [4]. Patients commonly experience a range of symptoms during and after their cancer care that can include pain, nausea, fatigue, sleep disturbances, and mood disorders [5]. Symptoms experienced by caregivers can include domains of physical, psychosocial, and financial distress [3]. Prior studies have examined self-reported symptoms for patients and caregivers, demonstrating correlations in psychosocial symptoms (depression, anxiety, well-being, financial distress, and spiritual pain) and overall distress [6–9]. Additional research exploring the effects of poor health of a spouse on partner

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This manuscript is not under consideration elsewhere. The study was conducted as part of an IRB approved protocol.

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health in the setting of cancer care has revealed the presence of a bi-directional (cancer patient to partner as well as from partner to patient) “spillover” effect, negatively impacting areas of mental and physical health-related QOL for the dyad [10]. Such findings support the importance of considering concurrent symptom and QOL screening strategies for patient and partner during cancer care.

One area of investigation has focused on understanding how well caregivers are able to perceive patient symptom burden in the context of cancer care. The current literature has examined concordance between two symptom scores: patient self-reported symptoms and caregiver perception of patient symptom distress. Findings have suggested that when a patient is unable to complete an evaluation of self-reported symptoms, caregivers may serve as a reliable proxy [7, 11]. One such study demonstrated higher agreement for symptoms when the caregiver in the couple was female, suggesting potential influence of demographic factors such as gender on concordance [8]. Prior results have also demonstrated greater agreement between patient and caregiver scores for physical versus psychosocial symptoms [7, 9, 12]. One study evaluating caregiver perception of symptom burden in patients undergoing cancer chemotherapy revealed caregivers overestimating the severity of the majority of patient symptoms assessed [13]. Perception of symptom burden and the associated distress may play a significant role in caregiver and patient health, with possible effects on long-term outcomes.

Although we are aware of the significant symptom burden experienced by both patient and caregiver, we know less about how couples’ perception of symptom burden can influence overall health and QOL. There has been an increased interest learning more about how couples perceive each other’s symptom burden and how this perception can have an effect on their overall experience of cancer care. The current study seeks to extend previous findings, examining differences between patient and partner perceptions of each other’s symptoms, with patient and partner each assessing their own symptoms and their perception of the other’s symptom distress.

## Methods

This study was conducted at the University of Texas MD Anderson Cancer Center’s Integrative Medicine Center between June 2015 and August 2016 as part of an IRB approved protocol. Patient and partners presenting for a clinical service (i.e., physician consultation, oncology massage, or acupuncture treatment) at the integrative medicine center were approached by a research assistant for participation in this study. Our goal was to recruit 100 participants (50 couples). Only patients with an eligible, consenting partner (i.e., spouse or romantic partner cohabiting for a minimum of 6 months) present during the time of the clinical encounter were approached. Eligibility criteria included patient having a

cancer diagnosis (any stage) and receiving active treatment for their cancer (systemic therapy, radiation), both patient and partner at least 18 years of age and having either member of the dyad receiving a clinical service in the integrative medicine center. After obtaining informed consent from patient and partner, we used a cross-sectional survey methodology with both patient and partner completing surveys independently; assessments took in total approximately 60 min to complete.

For purposes of this analysis, we report on responses to the Edmonton Symptom Assessment Scale (ESAS-FS) and Patient Reported Outcome Measurement Information System Global Health 10-item measure (PROMIS10) collected as part of the assessment battery. For the ESAS-FS, participants were instructed to complete their own symptoms as well as their perceptions of symptoms for the other member of the dyad on two separate forms without consulting the other. The PROMIS10 was completed only once by each participant for themselves. Participants were each given a \$10 gift card (\$20 per couple) after completion of the assessments.

## Measures

Participants completed demographic questions including sex, age, ethnicity, education level, employment status, income level, and marital status. Patients’ medical factors were extracted from the electronic medical record including disease type. Symptom and QOL assessments completed by patient and partner included the ESAS-FS and PROMIS10.

### Edmonton Symptom Assessment Scale

Patient and partner symptom burden was assessed using the ESAS-FS [14]. The ESAS-FS has been found to be an acceptable and feasible tool for assessing caregiver symptom burden [6]. It includes twelve symptoms: pain, fatigue, nausea, depression, anxiety, drowsiness, loss of appetite, decreased sense of well-being, shortness of breath, sleep, financial distress, and spiritual pain—as experienced in the prior 24 h on a numeric scale of 0 to 10, in which 10 is the worst possible expression of that symptom. The Global Distress Score (GDS) is the sum of pain, fatigue, nausea, drowsiness, appetite, shortness of breath, anxiety, depression, and well-being scores. The Physical Distress Score (PHS) is the sum of pain, fatigue, nausea, drowsiness, appetite, and shortness of breath. The Psychosocial Distress Score (PSS) is the sum of anxiety and depression. Patients and partner each completed two versions of the ESAS-FS: (1) rating their own symptoms and (2) rating the other’s symptoms (patients rated what they thought the partner was experiencing and partners rated what they thought the patient was experiencing). Higher scores represent worse symptom burden.

## PROMIS10 Global Health

The PROMIS10 [15] Global Health scale includes 10 self-report items that provides a global health score and can be divided to provide mental health (MH) and physical health (PH) scores. All items must be completed by the participant for proper scoring. Some of the responses require rescoring so that raw scores can be converted into T-score values, with T-score distributions standardized to the mean for the US population. Higher scores represent better QOL.

## Statistics

Summary statistics were used to present patient and partner demographic and clinical characteristics. A sample size of 50 couples has 80% power to detect a difference in effect size of 0.4, using a paired *t* test with a 0.05 two-sided significance level. When comparing self-rating and partner rating differences for each ESAS item, only those participants who had non-missing values on both self-rating and partner rating were included to calculate the mean symptom scores. Paired *t* test was used to examine self-rating and partner rating differences on the 12 individual ESAS-FS items, the GDS, the PHS, and the PSS subscales for both patient and partner separately. Paired *t* test was also used to examine the difference between patient and partner on the PROMIS10 Global Health scale and on the baseline self-ratings for ESAS-FS individual symptoms and subscales.

## Results

Fifty-six couples were approached with a final study sample of 50 couples (100 participants; 3 couples did not complete the study measures, 3 couples were ineligible). Patients had a mean age of 58.7, were 58% female, with most common cancer diagnoses of breast (22%), gastrointestinal (16%), and thoracic/head and neck (16%) [Table 1]. Partners had a mean age of 59.5 and were 44% female. The PROMIS10 Global Health scales revealed significantly lower overall patient global health [36.9 (SD 8.0) vs 42.9 (SD 7.7),  $p < 0.001$ ] and physical health [16.7 (SD 4.3) vs 20.2 (SD 4.0),  $p < 0.001$ ] versus their partners. There was, however, no significant difference between patient and partner on global mental health [14.2 (SD 3.4) vs 15.1 (SD 3.2),  $p = 0.1$ , respectively] (table not shown). Patient self-ratings were significantly higher than partner self-ratings for ESAS-FS symptoms of pain, fatigue, nausea, drowsiness, appetite, well-being, and shortness of breath [Table 2]. No significant differences between patient and partner were observed for symptoms of depression, anxiety, sleep, financial distress, and spiritual pain. GDS and PHS were significantly higher for patients versus partners, with no differences for PSS. Missing data was low, with 10% or less depending on the individual question.

**Table 1** Demographic and clinical characteristics of patients and partners

Demographics	Patient <i>n</i> (%)	Partner <i>n</i> (%)
Age		
<i>N</i>	47	48
Mean (SD)	58.7 (13.5)	59.5 (10.7)
Gender		
Male	21 (42%)	28 (56%)
Female	29 (58%)	22 (44%)
Marital status		
Married	49 (98%)	48 (96%)
Living with significant other	1 (2%)	2 (4%)
Caregiver status		
My spouse/partner	49 (98%)	43 (86%)
Other	1 (2%)	0
Missing	0	7 (14%)
Employment		
Employed full time	18 (36.7%)	23 (46.9%)
Unemployed	4 (8.2%)	3 (6.1%)
Housewife/homemaker	7 (14.3%)	7 (14.3%)
Employed part time	5 (10.2%)	1 (2.0%)
Retired	15 (30.6%)	15 (30.6%)
Ethnicity		
Anglo/Euro-American	40 (80%)	40 (80%)
Hispanic	4 (8%)	4 (8%)
African-American	1 (2%)	1 (2%)
Asian/Pacific Islander	1 (2%)	1 (2%)
Other	4 (8%)	4 (8%)
Education level		
Some high school or technical school but not a high school graduate	1 (2%)	0
High school graduate	6 (12%)	9 (18%)
Some college, associate degree	12 (24%)	13 (26%)
College graduate	12 (24%)	7 (14%)
Some graduate/professional school after college	19 (38%)	20 (40%)
Declined to answer	0	1 (2%)
Disease type		
Breast	11 (22%)	N/A
Gastrointestinal	8 (16%)	
Thoracic/head and neck	8 (16%)	
Myeloma/lymphoma	7 (14%)	
Genitourinary	5 (10%)	
Gynecologic	4 (8%)	
Other	6 (12%)	

## Patient self-rating and partner perception of patient

When comparing patient self-rating and partner ratings of patient symptoms using the ESAS-FS, partner rating of patient symptoms was significantly higher than patient self-rating for

**Table 2** Patient self-ratings and partner self-ratings of symptoms on the Edmonton Symptom Assessment System (ESAS-FS)

ESAS-FS symptoms	<i>n</i>	Patient self-rating mean (SD)	Partner self-rating mean (SD)	<i>p</i> value*
Pain	50	3.3 (3.0)	1.6 (2.3)	<i>0.002</i>
Fatigue	50	4.7 (2.7)	2.7 (2.5)	<i>&lt; 0.001</i>
Nausea	49	1.5 (2.1)	0.2 (1.2)	<i>&lt; 0.001</i>
Depression	50	1.6 (2.7)	1.1 (1.9)	0.2
Anxiety	50	2.1 (2.5)	1.9 (2.2)	0.6
Drowsiness	50	3 (3.1)	1.5 (2.0)	<i>0.001</i>
Appetite	50	3 (2.9)	1.2 (2.3)	<i>&lt; 0.001</i>
Well-being	50	3.7 (2.8)	2.6 (2.7)	<i>0.03</i>
Shortness of breath	50	0.98 (1.6)	0.3 (1.1)	<i>0.01</i>
Sleep	50	4.3 (2.9)	3.7 (2.7)	0.2
Financial distress	49	2 (2.9)	2.5 (3.0)	0.2
Spiritual pain	46	0.9 (1.6)	0.8 (1.5)	0.7
Global Distress Score	49	24.2 (16.5)	13.2 (11.7)	<i>&lt; 0.001</i>
Physical Distress Score	49	16.6 (11.2)	7.6 (6.9)	<i>&lt; 0.001</i>
Psychosocial Distress Score	50	3.8 (5.0)	3 (3.8)	0.3

\*Paired *t* test; values in italics statistically significant, *p*<0.05

symptoms of pain, fatigue, nausea, depression, anxiety, well-being, shortness of breath, and financial distress [Table 3]. Patient self-rating for symptoms of drowsiness, appetite, sleep, and spiritual pain was not significantly different from partner rating of patient for these symptoms. Patient self-ratings on the ESAS-FS subscale scores of GDS, PHS, and PSS were significantly lower than the partner ratings of the patient.

### Partner self-rating and patient perception of partner

When comparing partner self-rating and patient ratings of partner symptoms using the ESAS-FS, partners rated their own symptoms of pain and fatigue significantly lower than patient rating of partner symptoms [Table 4]. For all other symptoms, there were no significant differences in partner self-rating and patient rating of partner. Partner GDS and

**Table 3** Patient self-ratings and partner ratings of patient on the Edmonton Symptom Assessment System (ESAS-FS)

ESAS-FS symptoms	<i>n</i> *	Patient self-ratings mean (SD)	Partner rating of patient mean (SD)	<i>p</i> value**
Pain	50	3.3 (3.0)	4.3 (2.8)	<i>0.006</i>
Fatigue	50	4.7 (2.7)	5.7 (2.6)	<i>0.002</i>
Nausea	50	1.5 (2.1)	2.2 (2.8)	<i>0.04</i>
Depression	50	1.6 (2.7)	2.7 (2.6)	<i>0.002</i>
Anxiety	50	2.1 (2.5)	3.5 (2.6)	<i>&lt; 0.001</i>
Drowsiness	50	3.0 (3.1)	3.3 (2.8)	0.4
Appetite	50	3.0 (2.9)	3.4 (3)	0.2
Well-being	50	3.7 (2.8)	4.7 (2.5)	<i>0.01</i>
Shortness of breath	50	0.98 (1.6)	1.8 (2.5)	<i>0.004</i>
Sleep	50	4.3 (2.9)	4.4 (3.1)	0.9
Financial distress	49	2.0 (2.9)	2.9 (3.1)	<i>0.02</i>
Spiritual pain	47	0.9 (1.6)	1.04 (1.9)	0.6
Global Distress Score	50	23.9 (16.5)	31.8 (16.4)	<i>&lt; 0.001</i>
Physical Distress Score	50	16.5 (11.1)	20.9 (11)	<i>0.001</i>
Psychosocial Distress Score	50	3.8 (5)	6.2 (5)	<i>&lt; 0.001</i>

\*Only those participants who had non-missing values on both self-rating and partner ratings on each item were included to calculate the means; missing data no greater than 6% (3/50; spiritual pain item)

\*\*Paired *t* test; values in italics statistically significant, *p* < 0.05

**Table 4** Partner self-ratings and patient ratings of partner on the Edmonton Symptom Assessment Scale (ESAS-FS)

ESAS-FS symptoms	<i>n</i> *	Partner self-ratings mean (SD)	Patient rating of partner mean (SD)	<i>p</i> value**
Pain	48	1.5 (2.3)	2.5 (2.7)	<i>0.001</i>
Fatigue	48	2.6 (2.4)	3.2 (2.6)	<i>0.04</i>
Nausea	47	0.2 (1.2)	0.3 (1.0)	0.2
Depression	47	1.1 (1.9)	1.5 (1.8)	0.3
Anxiety	47	2 (2.2)	2.3 (2.2)	0.4
Drowsiness	47	1.5 (2)	2 (2.5)	0.08
Appetite	47	1.3 (2.3)	1.8 (2.4)	0.3
Well-being	47	2.7 (2.8)	3 (2.6)	0.5
Shortness of breath	47	0.3 (1.1)	0.3 (0.8)	0.8
Sleep	47	3.7 (2.8)	3.6 (2.7)	0.9
Financial distress	46	2.5 (3.1)	2.1 (2.9)	0.3
Spiritual pain	45	0.8 (1.5)	1.1 (1.7)	0.4
Global Distress Score	46	13.2 (12)	17 (13.1)	<i>0.04</i>
Physical Distress Score	46	7.4 (7)	10.2 (8.6)	<i>0.01</i>
Psychosocial Distress Score	47	3.1 (3.9)	3.7 (3.7)	0.3

\*Only those participants who had non-missing values on both self-rating and partner ratings on each item were included to calculate the means; missing data no greater than 10% (5/50; spiritual pain item)

\*\*Paired *t* test; values in italics statistically significant, *p* < 0.05

PHS subscale scores were significantly lower than the patient ratings of the partner, with no significant differences in PSS scores.

Overall, only when comparing symptoms of drowsiness, appetite, sleep, and spiritual pain, were there no significant differences between patient-self and partner [Table 3] and partner-self and patient [Table 4] symptom perceptions [NB: patient and partner self-rating outcomes differ between Tables 2, 3, and 4 due to differential missing data].

## Discussion

In this study, we explored the association between patient and partner symptom self-ratings and how they perceive each other's symptom burden. For ESAS-FS self-ratings, we observed significant differences in patient and partner physical symptom burden represented by higher symptom scores in patients for pain, fatigue, drowsiness, appetite, nausea, and shortness of breath. There was overall higher global distress and physical distress in patients, with no significant differences in psychological distress between patients and partners. When examining the PROMIS10 Global Health measure, we again observed lower physical health and global health for patients, with no significant differences in global mental health between patients and partners.

Patient and partner symptom burden in this study is consistent with our prior experience. We have previously

examined symptoms of patients presenting for an integrative medicine physician consultation [16]. For the physician consultation, patient symptoms of fatigue and sleep were within the moderate range (moderate defined as symptom score range 4–7) and other symptoms fell in the low range (low defined as symptom score range 0–3). We have also examined symptoms of patients and caregivers presenting for massage treatment [17]. For massage treatment, patient mean sleep scores were in the moderate range, with other patient and caregiver symptom scores falling in the low range. Of note, patient symptom burden in our study is lower compared to symptoms of advanced cancer patients presenting for a supportive care consultation at a comprehensive cancer center [18].

When comparing patient self-rating of symptoms to partner rating of patient symptoms, we saw that overall partner ratings of patient symptoms were higher than patient self-ratings. This pattern has been observed in prior research examining caregiver perception of patient symptom burden [13]. For individual symptoms of drowsiness, appetite, sleep, and spiritual pain, there were no significant differences in patient-partner symptom ratings. However, the ESAS-FS subscales of global distress, physical distress, and psychosocial distress were all rated significantly higher for the partners' perception of the patient relative to the patient's own self-assessment. This suggests that partners are overestimating the symptoms patients are experiencing.

Novel to this study is the inclusion not only of partner/patient self-rating, but having patients provide ratings for

their perception of partner symptoms. Our results show patients serving as a better proxy for partner symptoms than partners serving as a proxy for patient symptoms. On examination of individual ESAS-FS partner symptoms as perceived by the patient, the only observed differences were patients overestimating partner symptoms of pain and fatigue. On examination of partner ESAS-FS subscale scores, patients overestimated partner Global Distress and Physical Distress Scores, but not Psychosocial Distress. Our results suggest that patients are better at perceiving psychosocial distress of their partners. In general, both partners and patients tended to overestimate each other's symptom burden, with partners overestimating on more areas.

On review of self-rating versus rating of the other, only for symptoms of drowsiness, appetite, sleep, and spiritual pain were there no significant differences in perceived symptom burden. This suggests that these symptoms represent areas in which couples are most successful in perceiving each other's distress. Further efforts should be made to explore reasons for this observation as part of additional efforts to examine strategies to improve symptom perception across other symptoms.

There are a number of limitations to the current study. Our study focused on partners in a romantic relationship, therefore providing limited insight into symptom perception of non-romantic partners/caregivers. An additional limitation with regard to generalizability of results includes a higher representation of individuals with Anglo/Euro-American ethnicity and college degree or more in our sample. A higher representation of breast cancer patients versus other disease types was expected considering the recruitment location was an integrative medicine center where the majority of patients seeking care in such a setting have breast cancer. However, this limits the generalizability of our findings.

Our findings provide insight into how patients and their partners perceive each other's symptoms. Although prior research has examined caregiver perceptions of patient symptoms, to our knowledge, this is the first study to examine patient perception of partner symptom burden. In general, both patients and their partners tended to overestimate the symptom burden the other was experiencing, yet patients tended to be more accurate overall. Extensive research shows clear reciprocity in patient-caregiver QOL and managing symptoms in caregivers as having a significant role in improving patient QOL [13]. Strategies aimed at improving patient-partner communication regarding symptom burden may lead to improvements in symptom perception. Giving patient and partner the opportunity to complete an assessment of self and other ratings during a clinical encounter using a tool such as the ESAS-FS may serve as a helpful prompt for discussions regarding symptom expression and perception.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

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