Financial distress and its associated burden in couples coping with an advanced cancer

Juliet L. Kroll1 · Seokhun Kim1 · Dalnim Cho2 · Shiao-Pei Weathers3 · Aileen B. Chen4 · Grace Smith2,4 · Eduardo Bruera5 · Kathrin Milbury1

Received: 27 May 2021 / Accepted: 13 December 2021 / Published online: 3 February 2022
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Purpose In efforts to understand financial distress (FD) associated with advanced cancer care from the perspective of both patients with incurable disease and their spousal caregivers, we assessed FD in both members of the couple, identified symptom and quality of life (QOL) correlates, and examined the potential role of illness communication.

Methods Patients undergoing treatment for stage III/IV lung cancer or a grade III/IV primary brain tumor and their spousal caregivers (n = 76 dyads) completed measures of somatic and affective symptoms including FD, physical and mental QOL, and ease of engaging in illness communication. Patients and caregivers additionally rated their perception of each other’s symptoms, including FD.

Results FD was endorsed by both patients (any FD 62.7%; high FD 24%) and spousal caregivers (any FD 64.7%; high FD 32.3%). Self-reported FD was significantly correlated (partial r = .52, p < .001) within couples. FD was associated with greater symptoms of anxiety (r = .29, p = .01; r = .31, p = .01), depression (r = .29, p = .01; r = .39, p = .001), and poorer physical QOL (r = −.25, p = .03; r = −.25, p = .001) for patients and caregivers, respectively. For patients, FD was additionally associated with poorer mental QOL (r = −.44, p < .001). Caregivers accurately perceived patient FD, yet patients tended to underreport their caregiver’s FD by almost an entire point (t = 2.8, p = .007). A 3-way interaction (FD X role X illness communication) revealed (b = .40, p = .041) that illness communication moderated the association between FD and physical QOL for spouses so that spouses who reported less ease of illness communication demonstrated a stronger association between financial distress and physical QOL (b = −2.08, p < .001) than those reporting greater ease of engaging in illness communication (b = .49, p = .508).

Conclusion In the advanced cancer setting, FD is prevalent in both patients and their spousal caregivers and associated with psychological distress and poor physical QOL. Results suggest that optimal FD assessment should include patients and spouses, and spouse’s ease of engaging with illness communication may be a potential target for future intervention studies.

Keywords Financial distress · Couples · Advanced cancer · End-of-life · Physical quality of life · Illness communication

Introduction

The burden accompanying a cancer diagnosis and subsequent treatment is experienced by both the patient and their family members, who are increasingly involved in caregiving roles during treatment and at end-of-life. Among family caregivers, the spouse or romantic partner (hereafter referred to as spousal caregiver) often serves as the primary source of both instrumental and emotional support [1]. This provision of support does not come without challenges and is widely conceptualized as “caregiving burden” [2]. Caregiving burden is particularly high in those caring for a patient with an advanced/incurable cancer [3]. Of note, caregiving burden is
associated with poorer physical and emotional health of the caregiver and poorer quality of life (QOL) of the patient [1]. One increasingly identified consequence of cancer treatment which impacts both the patient and their spousal caregiver is financial toxicity (FT), comprised of (1) the objective material financial burden (e.g., co-pays and out-of-pocket (OOP) costs); (2) behavioral consequences (e.g., lost job) associated with cancer treatment, and (3) financial distress (FD), the subjective psychological experience of financial concerns. As cancer costs and OOP patient expenses continue to rise [5], the deleterious sequelae of objective financial burden on patient outcomes and cancer care will likely persist [6, 7]. Indeed, studies observe that one’s increase in objective financial burden, captured by the ratio of OOP medical costs to earnings, is associated with self-report measures of FT broadly [8]. However, the subjective psychological experience of FD may only be moderately correlated to the objective financial burden, similar to patterns observed in other patient self-reports—such as neurocognitive difficulties [9]. The past two decades of psychosomatic study of stress broadly identify that the largest driver of both psychological and physiological responses to stress is often not the objective frequency of exposure to a stressor. Rather, one’s subjective perception of the stressor is often the strongest predictor of psychological and physiological responses to stress [10, 11], which has downstream outcomes identified to create a more fertile environment for tumor progression and metastases [12]. As such, the present study is specifically designed to capture the subjective perception of FD for both patients and their spousal caregivers.

In the palliative setting, FD may be particularly relevant [13]. Cancer costs typically follow a “u-shaped” temporal curve with the highest objective burden at diagnosis and end-of-life [14], poorer overall health and functional status are associated with greater self-report of FT [15], and in advanced cancer patients over age 70, self-report of FT is associated with greater psychological distress and lower health-related QOL [16]. Furthermore, FD in advanced cancer patients is associated with greater somatic and affective symptom burden (e.g., ratings on the Edmonton Symptom Assessment Scale (ESAS)), in both US and international samples [17, 18]. As treatment goals for patients with incurable disease often aim to prolong life while maximizing QOL, FD is a highly relevant topic to QOL that has until recently received little attention in supportive care settings.

Accumulating research illuminates the deleterious impact of objective economic burden experienced by cancer patients [19, 20], spousal caregivers [21–23], and the pediatric patient-parent caregiver dyad [24]. However, FD from the patient-spousal caregiver dyadic perspective remains surprisingly unexplored in cancer. Members of a romantic couple often have unique psychological responses to a shared stressor [25]; thus, it is plausible that even though the objective economic burden of cancer is shared, the subjective psychological experience of FD may be distinctly experienced by each member of the couple. A spouses’ psychological state often impacts that of their patient, and vice versa, resulting in an interdependence of both psychological state and QOL among couples facing cancer [26, 27]. Physical health is additionally observed to be interdependent in couples [28], yet not all studies find this association in cancer patients [29]. This interdependence reaffirms the value of examining both the patient and spousal caregiver’s perspectives of FD, in that the physical or mental health status of the spousal caregiver may indicate a greater risk of psychological distress or poorer physical QOL for their patient and vice versa. One component likely contributing to this interdependence is how a couple communicates. For cancer patients specifically, Manne and colleagues [30] observe that avoidance of discussing cancer-related issues within the couple is associated with poorer outcomes for both patients and their spousal caregivers. Furthermore, when one member of the couple “holds back” and avoids discussing a topic of personal importance, even if conducted with good intentions of not wanting to alarm their patient or increase potential sources of stress, it can be detrimental to couples’ relationship satisfaction and emotional well-being [31]. Seminal laboratory studies identify that emotional suppression not only contributes to psychological distress, but also has distinct physiological and sympathetic consequences [32]. Therefore, capturing both members of the couples' personal experience of illness communicating and how they perceive their spouse to communicate illness concerns with them may provide specific insight into how illness communication may reduce or strengthen the association between FD and both mental and physical QOL.

The goal of the present study is to assess the intensity and relative severity of FD in patients and their spousal caregivers and further identify associated psychological symptom and overall QOL correlates as a first step to understand how couples approach this concern. In an effort to identify targets for future interventions to support patients and their spousal caregivers experiencing FD, we will explore if illness communication moderates the relation between FD and both mental and physical QOL using dyadic analyses.

**Method**

**Participants**

In the present study, 76 adult patients with a diagnosis of stage III-b or IV non-small cell lung cancer (NSCLC) or grade III or IV primary brain tumor undergoing treatment (e.g., chemotherapy, surgery, and/or radiotherapy) and their spousal caregiver (e.g., spouse or romantic partner with...
whom the patient has cohabitated > 6 months) were enrolled from a large comprehensive cancer center. Patients with cognitive deficits, as indicated by their clinical team, were excluded. All participants were fluent in English.

Glioma and advanced lung cancer patients were specifically selected for this smaller initial study, due to their similar nature of poor prognosis, sex distributions, and the substantial and rapid change caregiving responsibilities, which may capture two relatively complementary disease groups with particularly high caregiving burden rather than an entirely mixed cancer sample for this smaller pilot study. Recent studies additionally highlight that glioma patients may be particularly vulnerable to high rates of FT, warranting additional insight into this population [33].

Procedures

Participants were identified through the electronic health record (EHR), recruited in their respective clinics by research staff, further screened at their clinic visit, and, if eligible, provided written informed consent. If the spousal caregiver was not present at the initial visit, permission was obtained from the patient to contact the caregiver by phone to obtain consent. We approached 100 consecutive eligible dyads and 76 consented. Primary reasons for patients to decline participation was “lack of interest” and being “too busy.” Participants completed a series of validated questionnaires by pen and paper. The University of Texas MD Anderson Cancer Center Institutional Review Board approved the study. Participants were compensated for their time.

Measures

Demographics and medical details

Participants provided demographic information including age, sex, race/ethnicity, employment status, education, and type of relationship with spousal caregiver (e.g., married or domestic partner). Disease stage/grade and time since diagnosis were extracted from the EHR.

Financial distress (FD) and general symptoms

FD and general symptoms were captured by the Edmonton Symptom Assessment Scale – Financial Spiritual (ESAS-FS), a 12-item measure of common cancer-related symptoms where patients rate their present experience (i.e., “right now”) on a 0–10 Likert-type scale, with 10 indicating greatest severity of symptom [34]. Topics range from appetite to pain to spiritual pain, and have been validated in caregiver samples [34]. FD was extracted as a single item from the ESAS-FS, with 0 indicating “no financial distress” and 10 indicating “worst financial distress.” All participants rated both the severity of their own symptoms (including FD) following the prompt “Please answer as they pertain to you” and separately for their spouse to capture a “proxy report” following the prompt “Please answer as they pertain to your partner (spouse).” Of note, in prospective studies, a single point difference on the self-reported ESAS-FS is interpreted as clinically meaningful [34]. Routinely utilized cutoffs include 1–3 for mild symptoms, 4–6 for moderate symptoms, and 7–10 for severe symptoms [34].

Psychological distress

Psychological distress was captured with two self-report measures. Symptoms of anxiety were captured with the 6-item anxiety subscale of the Brief Symptom Inventory (BSI-18) [35]. Participants rated their experience of anxiety over the past week ranging from 0 “not at all” to 4 “extremely.” Scores on the anxiety subscale can range from 0 to 24. Depressive symptoms were captured by the 20-item Center for Epidemiological Studies—Depression (CES-D). Participants rated the frequency of depressive symptoms over the past week on a scale ranging from 1 “almost never” to 4 “almost always (5 to 7 days).” Scores greater than 16 indicate a likely mild case of clinical depressive episode, with scores greater than 26 indicating a moderate to severe presentation [36].

Mental and physical QOL

Mental and physical QOL were assessed with the 10-item PROMIS Global Health short form. Participants rated QOL on a 5-point Likert-type scale ranging from 1 “Poor” to 5 “Excellent.” The final item subscales were scored for both global physical QOL and global mental QOL [37].

Illness communication

Each participant’s perceived ease of illness communication within the couple was captured with the Couples’ Illness Communication Scale (CICS), a brief 4-item self-report measure [38]. This scale captures each member of the couple’s own personal ease discussing topical issues and feelings related to cancer, along with their perception of their partner’s willingness or reluctance discussing topical issues and feelings surrounding illness. Participants rated their response to each statement on a Likert-type scale, ranging from 1 “disagree strongly” to 5 “agree strongly.” For example, “It is hard for me to express feelings about my illness to my partner” [38]. Scores range from 1–20 with higher scores indicating greater personal ease of illness communication and a stronger impression of their spouse’s willingness to communicate about cancer. Low scores are interpreted as a reluctance to discuss illness-related topics within the couple.
Analytic plan

First, descriptive statistics (i.e., frequencies for categorical variables and means, standard deviations, and partial correlations for continuous variables) were calculated to describe the sample and variables of interest. Paired sample t-tests for continuous and chi-squared tests for categorical variables were conducted to examine group differences between patients and spouses across all variables. Second, bivariate Pearson correlations among continuous variables of interest were run separately for patients and spousal caregivers. Third, analysis of variance ANOVAs or Pearson correlations were used to examine associations between demographics (i.e., sex, education, employment status, race, ethnicity, age) or medically relevant details (i.e., disease site, disease stage, time since diagnosis) and FD. Fourth, in order to examine if illness communication moderated the associations between FD and mental QOL and physical QOL, we conducted separate dyadic analyses using a multi-level modeling (MLM) approach to account for our nested data structure (individuals within dyads) [39]. As disease site, age, sex, education, and employment status have all been previously associated with objective financial burden [15], MLM analyses controlled for these covariates. For ease of interpretation, illness communication (CICS) was grand mean centered. Full information maximum likelihood method was used to deal with missing data in the outcomes. Finally, we conducted Actor Partner Interdependence Models (APIM), using a MLM approach with double-entry structure to model within-couple non-interdependence between patient and spouse [39]. The actor effect assessed if a participant’s FD score is associated with their own mental QOL and physical QOL. The partner effect assessed if a participant’s FD is associated with their spouse’s FD, mental QOL, and physical QOL. SPSS 24 was used for descriptive statistics, correlations, and regression analyses. Stata 16 was used for MLM including the APIM analyses.

Results

Descriptive statistics

A total of 152 participants (e.g., 76 couples) participated in the study. For patients, mean age was 58.19 years (SD = 12.31); approximately half were female (50.7%) and the majority had an opposite-sex spouse (n = 3 had same-sex spouse). Most patients were well-educated (44.4% had a college degree), non-Hispanic White (81.4%), and retired (46.5%) (see Table 1). For spouses, the mean age was 57.83 years (SD = 13.12). Spouses also tended to be well-educated (49.6% college graduate), non-Hispanic White (80.3%), and over half employed full-time (50.7%). Patients reported mild-to-moderate levels of psychological distress (BSI-18: M = 0.31, SD = 0.34; CES-D: M = 10.69, SD = 7.3), with spouses reporting greater anxiety (BSI-18: M = 0.46, SD = 0.45; t = 2.77, p = 0.007). Both patients and their spouses reported high illness communication (CICS: M = 16.74, SD = 3.1; M = 15.67, SD = 3.6 respectively), which was significantly greater in patients (t = 2.38, p = 0.040). As expected, patients reported poorer physical QOL than their spouses (t = −3.01, p = 0.003), yet there was no group difference in mental QOL (see Table 1).

Frequency and relative severity of FD

In patients, 62.7% reported presence of FD (defined as scores of 1 or greater) and 24% reported high FD (defined as a score of 4 or greater) [40]. In spousal caregivers, 64.7% reported presence of FD and 32.3% reported high FD. On average, patients and spousal caregivers reported mild levels of FD (M = 2.32, SD = 2.81, M = 2.81, SD = 3.12 respectively), where scores 1–3 specify mild distress. Among the 12 common cancer symptoms assessed, patients rated FD as the 7th most severe symptom. In turn, spouses rated their own FD as the 2nd most severe symptom (after sleep disturbances) (see Table 2 and Fig. 1).

Participant characteristics associated with FD

For patients, women reported more FD than men (F(1,72) = 5.93, p = 0.017). Education history varied by degree of FD (F(3,66) = 2.54, p = 0.036), where patients with some graduate school reported the greatest FD (M = 4.80, SD = 1.93). For spouses, none of the demographic variables were significantly associated with FD at p < 0.05.

Symptoms associated with FD

For patients, FD was associated with greater depressive symptoms (CES-D, r = 0.29, p = 0.010), anxiety (BSI-ans, r = 0.29, p = 0.010), and poorer physical QOL (PROMIS, r = −0.25, p = 0.030). For spouses, FD was associated with greater depressive symptoms (r = 0.39, p = 0.001), anxiety (r = 0.31, p = 0.010), poorer physical QOL (r = −0.38, p = 0.002), and poorer mental QOL (r = −0.44, p < 0.001) (see Table 3).

Self-report and partner proxy report of FD

While spousal caregivers accurately rated the FD of their patient (r = 0.54, p = 0.590), patients tended to underperceive the extent of their spouse’s experience of FD by an entire point (r = 2.80, p = 0.007) (Table 4). As expected, patients’ and spouses’ self-report of FD were correlated (partial r = 0.53, p < 0.001), controlling for couple membership.
(see Tables 4 and 5 for comparison between self-report and spouse proxy report on ESAS-FS).

**Symptoms associated with illness communication**

For both patients and spouses, greater ease of illness communication captured by the CICS was associated with fewer symptoms of anxiety, \( r = -0.239, p = 0.046; r = -0.371, p = 0.001 \), respectively. For spouses only, greater ease of illness communication was additionally associated with fewer symptoms of depression \( r = -0.382, p = 0.001 \) along with greater physical \( r = 0.271, p < 0.001 \) and mental QOL \( r = 0.326, p = 0.005 \). FD was not correlated with illness communication for either member of the couple (see Table 3). Overall, patients’ and spouses’ reports of illness communication were moderately correlated, \( r = 0.361, p = 0.002 \), controlling for couple membership.

**Dyadic models of FD**

**Physical QOL**

MLM analyses revealed that the association of FD with physical QOL significantly varied by role and across
illness communication (FD X role X illness communication) ($b = 0.37$, $p = 0.039$), controlling for disease site, age, sex, education, and employment (Fig. 2). When illness communication was low ($−1$ SD from its mean) indicating a greater reluctance to discuss components of illness, spouses demonstrated a stronger association between FD and physical QOL ($b = −2.08$, $p < 0.001$) than when their illness communication was high ($+1$ SD from its mean) ($b = 0.49$, $p = 0.508$). For patients, the negative association between FD and physical QOL did not differ if patients were
high ($b = -1.15, p = 0.05$) or low in illness communication ($b = -1.18, p = 0.06$) (see Fig. 2 for graphical representation). APIM analyses did not reveal significant partner effects for FD and physical QOL.

### Mental QOL

No three-way interaction, two-way interactions, or main effects were found among FD, mental QOL, and illness communication in either patients or spousal caregivers for this sample. No partner effects were observed for FD and mental QOL.

### Discussion

This cross-sectional survey was designed to assess the prevalence, intensity, and relative severity of FD along with any associated symptoms of psychological distress and QOL in both patients with advanced cancer and their spousal caregivers. Whereas (FT) has been studied in a variety of advanced cancer settings, to the best of our knowledge, this is the first study to examine FD at the analysis level of the couple—the relationship where financial concerns and caregiving are most intimately navigated.
subjective perception of financial distress remains prevalent and even at mild levels and is associated with greater psychological distress and poorer quality of life. As those approaching and into retirement may be in periods of financial transition due to life stage, they may be more psychologically vulnerable to financial distress although they may have less objective financial burden. Finally, findings that identify education level to be associated with FD should be cautiously interpreted given the small sample size \((n = 5)\) of advanced cancer patients who only attended “some graduate school.” This study is only a first step in and conceptualizing FD at the level of the couple, with research urgently needed to fully capture the construct of FD across ranges of socioeconomic status.

**Symptoms associated with FD**

Despite general ratings of mild FD, FD in patients was associated with greater symptoms of anxiety and depression as well as poorer physical QOL, consistent with other studies of FD \([17, 18, 40]\) and objective financial burden \([7, 16, 22, 23]\). This highlights that even at mild intensity, FD is associated with other domains of patient distress. What was observed for the first time here is that spousal caregiver FD is also associated with greater symptoms of anxiety, depression, and poorer physical QOL. While cross-sectional in nature, the associated symptom and QOL correlates suggest that the subjective FD is not only an important component of patient experience but may also be a unique component of caregiver burden.

**Proxy ratings of FD**

Despite the general tendency of spousal caregivers to overestimate symptoms in their patients \([43]\) (and who did so here on 7 out of 12 symptoms), spousal caregivers accurately estimated their patient’s FD. On the other hand, patients tended to underestimate their spousal caregiver’s FD by an entire point. A single point difference can lead to different clinical interpretations \([34]\). It is plausible that patients, more cognitively focused on their own present symptom burden, find it difficult to imagine the future-oriented financial concerns of their spouse. Additionally, spousal caregivers may limit raising any apprehension regarding present or future financial responsibilities directly with the patient out of concern for adding additional stressors. In fact, this intended “protective buffering” is well documented in couples coping with cancer \([44, 45]\). While the couple’s perceived ease of discussing cancer-related topics and emotional experience was reported at high levels by both patients and spousal caregivers, the extent to which couples specifically discussed finances was not captured.

---

**Prevalence of FD**

FD was present in over 60% of the sample and endorsed at a high level in 24% of patients and 34% of caregivers. On average, there was a high degree of concordance (i.e., correlation) of FD within the couple. These rates reinforce the relevance of the psychological experience of FD—even for insured families treated at comprehensive cancer centers \([41, 42]\). Yet, compared to patient samples with similar demographics and diagnoses of advanced cancer treated at comprehensive cancer centers, the present sample endorsed lower severity of FD \([26, 43]\). This may potentially be attributable to the partnered nature of this sample, as unpartnered status can predict both FD and FT \([8, 41]\). Furthermore, a majority of the spousal caregivers were still either working or retired, indicating the likelihood of continued economic stability. Additionally, couples in this population were largely older (> 55), where rates of FT are observed to be lower than in younger samples \([15]\). Compared to samples collected at safety-net hospitals with greater inclusion of uninsured patients with less formal education history and comprised of a greater proportion of traditionally underrepresented minority patients, the present sample reported lower prevalence rates and severity of FD. Taken together, sample characteristics suggest that couples in the present sample likely benefited from higher socioeconomic status, prior to their cancer diagnosis and access to insurance, which has likely supported their objective economic position. While these families may experience less of the objective material financial burden than those without insurance, their financial burden.
Moderating effects of illness communication

Dyadic analyses revealed a moderating effect of illness communication on the association between FD and physical QOL for the spousal caregiver. Seminal studies in couples coping with cancer identify that the avoidance of cancer-related communication is associated with negative consequences of both patient and spousal well-being, and in turn mutual constructive communication is associated with less psychological distress [45]. While illness communication did not appear to be directly associated with FD, spousal caregivers reporting low illness communication, which incorporates both personal discomfort with cancer-related topics and a perception that their patient is reluctant to discuss cancer-related topics or emotional aspects of their disease, appeared to have a stronger negative relation between FD and physical QOL. Interestingly, this was only observed in spousal caregivers. As spouses appear to experience a greater relative burden of FD than patients, there may have been greater variability to detect associations in this sample. Additionally, other findings of cancer patients (although not necessarily with advanced disease) observe that when the spousal caregiver perceives the patient has greater non-disclosure, the caregiver rates higher distress [32]. Exploratory analyses in previous studies conducted in prostate cancer patients, looking at holding back in discussing cancer-related issues within the couple, found that holding back on financial issues by the patient was associated with poorer intimacy (composite measure including both emotional and physical), relationship satisfaction, and distress [31]. Of cancer-related concerns, financial issues were least strongly associated with outcomes for patients yet were the most strongly associated with lower intimacy for spouses [31], underscoring the unique role that financial issues may play for the spouse.

These initial findings presented here cautiously suggest that for couples facing advanced cancer willingness to engage in illness communication may have a protective effect against the negative association of FD with physical QOL. A prospective study is needed to identify any directional associations; however, these initial findings cautiously suggest that illness communication may have a protective effect on the negative sequelae of FD. It is worth highlighting that the present study did not assess the frequency or ease of discussing financial concerns. As is called for in the general relationship literature [46], future research is needed on the potentially unique patterns depending on the topic of communication (i.e., finances, cancer, other relational topics).

Limitations and future directions

The present study has several limitations. The cross-sectional design precludes any directional or causal inferences. Equally relevant, the sample collected at a comprehensive cancer center does not incorporate the perspectives of those who are uninsured and likely experiencing the greatest degree of financial burden. Furthermore, a large proportion of non-Hispanic and White patients yields findings which are unlikely to sufficiently capture the experience of traditionally underrepresented minority patients who are observed to experience FT at some of the highest rates [15]. Future study is essential to fully capture the distinct psychological experience of FD across the spectrum of objective financial burden.

A notable limitation both here and in the field remains in the measurement of FD. While FD was measured consistently with previously published studies [17, 41, 43], there is no standardized measurement tool for FD (in contrast to measures for financial toxicity (FT)). As the study of FT, which encompasses FD, continues to develop, the generation of a brief psychometrically valid tool or subscale to capture the perceived psychological experience of FD is warranted. In addition, the present study did not capture the objective financial burden (i.e., income, ratio of income, or other financial support to expenses). Simultaneous measurement of all components of FT at economic, behavioral, and psychological self-report levels will be essential for conceptual and practical progress in addressing economic consequences of cancer treatment.

Despite the present limitations, these first findings at the level of the couple help to identify potential targets for assessment and intervention. As patient-level interventions designed to target FT of cancer care are only in their infancy [33, 47, 48], the findings here highlight opportunities to include the caregivers both in the FD assessment and as a target of individual-level intervention. Future examination if manipulating a spousal caregiver’s illness communication generally or specifically regarding finances (i.e., introducing strategies to increase communication) might help to buffer against the burden of FD with physical QOL being additionally warranted.

Clinical implications

The present study underscores the importance of assessing FD in both patients with advanced cancer and their spousal caregiver, particularly as patients tended to underreport their spouse’s FD by a clinically meaningful difference. For both members of the couple, even a mild report of FD is associated with greater psychological distress and poorer physical QOL.

Author contribution ILK, KM, EB, and GS conceptualized the study. JK, SK, and DC analyzed the data. SW and ABC were involved with data collection. All authors contributed to the writing of the manuscript.
Funding A portion of Dr. Kroll’s work on this manuscript was supported by funding from the Cancer Prevention and Research Institute of Texas (RP170259). A portion of Dr. Cho’s work on this manuscript was supported by funding from the Department of Defense (W81XWH-19-1-0460).

Availability of data and material Data will be made available upon reasonable request by contacting the primary author.

Code availability Not applicable.

Declarations

Ethics approval This study was approved by the MD Anderson Cancer Center Institutional Review Board.

Consent to participate All participants provided written informed consent prior to participation in this study.

Consent for publication All authors contributed to this work and reviewed the final version.

Competing interests The authors declare no competing interests.

References

1. Kim Y, Kashy DA, Wellisch DK, Spillers RL, Kaw CK, Smith TG (2008) Quality of life of couples dealing with cancer: dyadic and individual adjustment among breast and prostate cancer survivors and their spousal caregivers. Ann Behav Med 35(2):230–238. https://doi.org/10.1007/s12160-008-9026-y

2. Fletcher BS, Miaskowski C, Given B, Schumacher K (2012) The cancer family caregiving experience: an updated and expanded conceptual model. Eur J Oncol Nurs 16(4):387–398. https://doi.org/10.1016/j.ejonor.2011.09.001

3. Clark MM, Rummans TA, Sloan JA et al (2006) Quality of life of caregivers of patients with advanced-stage cancer. Am J Hosp Palliat Care 23(3):185–191. https://doi.org/10.1177/1049996506289074

4. National Cancer Institute. Financial Hardship [cited 2020 March 3]. Available from: https://healthcaredelivery.cancer.gov/hardship/

5. Mariotto AB, Enewold L, Zhao J, Zeruto CA, Yabroff KR (2020) Medical care costs associated with cancer survivorship in the United States. Cancer Epidemiol Biomarkers Prev. https://doi.org/10.1158/1055-9965.EPI-19-1534

6. Zafar SY (2015) Financial toxicity of cancer care: it’s time to intervene. J Natl Cancer Inst. 108(5):djv370. https://doi.org/10.1093/jnci/djv370

7. Zullig LL, Peppercorn JM, Schrag D, Taylor DH Jr, Lu Y, Samsa G, Abernethy AP, Zafar SY (2013) Financial distress, use of cost-coping strategies, and adherence to prescription medication among patients with cancer. J Oncol Pract 9(6S):s60–s63

8. Baddour K, Fadel M, Zhao M et al (2021) The cost of cure: examining objective and subjective financial toxicity in head and neck cancer survivors. Head Neck 43(10):3062–3075. https://doi.org/10.1002/hed.26801

9. Freeman JR, Broshek DK (2002) Assessing cognitive dysfunction in breast cancer: what are the tools? Clin Breast Cancer 3(Suppl 3):S91–S99. https://doi.org/10.3816/cbc.2002.s.019

10. Clark MS, Bond MJ, Hecker JR (2007) Environmental stress, psychological stress and allostatic load. Psychol Health Med 12(1):18–30. https://doi.org/10.1080/13548500500429338

11. Cohen S, Janicki-Deverts D, Miller GE (2007) Psychological stress and disease. JAMA 298(14):1685–1687. https://doi.org/10.1001/jama.298.14.1685

12. Antoni MH, Dhabhar FS (2019) The impact of psychosocial stress and stress management on immune responses in patients with cancer. Cancer 125(9):1417–1431. https://doi.org/10.1002/cncr.31943

13. Rotter J, Spencer JC, Wheeler SB (2019) Financial toxicity in advanced and metastatic cancer: overburdened and underprepared. J Oncol Pract 15(4):e300–e307. https://doi.org/10.1200/JOP.18.00518

14. Yabroff KR, Land J, Kepka D, Mariotto A (2011) Economic burden of cancer in the United States: estimates, projections, and future research. Cancer Epidemiol Biomarkers Prev 20(10):2006–2014. https://doi.org/10.1158/1055-9965.EPI-11-0650

15. Smith GL, Lopez-Olivo MA, Advani PG et al (2019) Financial burdens of cancer treatment: a systematic review of risk factors and outcomes. J Natl Compr Cancer Netw 17:1184–1189

16. Arastu A, Patel A, Mohile SG et al (2020) Assessment of financial toxicity among older adults with advanced cancer. JAMA Netw Open 3(12):e2025810. https://doi.org/10.1001/jamanetworkopen.2020.25810

17. Delgado-Guay M, Ferrer J, Rieber AG et al (2015) Financial distress and its associations with physical and emotional symptoms and quality of life among advanced cancer patients. Oncologist 20(9):1092–1098. https://doi.org/10.1634/theoncologist.2015-0026

18. Mercadante S, Adicel E et al (2021) Financial distress and its impact on symptom expression in advanced cancer patients. Support Care Cancer 29:485–490. https://doi.org/10.1007/s00520-020-05507-9

19. Shankaran V, Unger JM, Darke A, Suga JM, Wade JL, Kourlas P, Sreenivasa R Chandana SR, O’Rourke MA, Satti S, Liggett D, Hershman DL, Ramsey SD (2020) Cumulative incidence of financial hardship in metastatic colorectal cancer patients: primary endpoint results for SWOG S1417CD. J Clin Oncol 38(15_suppl):7010–7010

20. Ramsey SD, Bansal A, Fedorenko CR et al (2016) Financial insolvency as a risk factor for early mortality among patients with cancer. J Clin Oncol 34:980–986

21. Van Houtven CH, Ramsey SD, Hornbrook MC, Atienza AA, van Ryn M (2010) Economic burden for informal caregivers of lung and colorectal cancer patients. Oncologist 15(8):883–893. https://doi.org/10.1634/theoncologist.2010-0005

22. Li C, Zeliadt SB, Hall JI et al (2013) Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective. Support Care Cancer 21(12):3461–3469. https://doi.org/10.1007/s00520-013-1931-3

23. Gürgis A, Lambert S, Johnson C, Waller A, Currow D (2013) Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. J Oncol Pract 9(4):197–202. https://doi.org/10.1200/JOP.2012.000690

24. Pelletier W, Bonk A (2015) Assessment of financial burden as a standard of care in pediatric oncology. Pediatr Blood Cancer 62(S3):S619–S631

25. Falconer MK, Kuhn R (2019) Dyadic coping in couples: a conceptual integration and a review of the empirical literature. Front Psychol 10:571. https://doi.org/10.3389/fpsyg.2019.00571

26. Jacobs JM, Shaffer KM, Nipp RD et al (2017) Distress is interdependent in patients and caregivers with newly diagnosed incurable cancers. Ann Behav Med 51(4):519–531. https://doi.org/10.1007/s12160-017-9875-3
27. Milbury K, Badr H, Fossella F, Pisters KM, Carmack CL (2013) Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. Support Care Cancer 21(9):2371–2379. https://doi.org/10.1007/s00520-013-1795-6
28. Meyler D, Stimpson JP, Peek MK (2007) Health concordance within couples: a systematic review. Soc Sci Med 64(11):2297–2310. https://doi.org/10.1016/j.socscimed.2007.02.007
29. Streck BP, Wardell DW, LoBiondo-Wood G, Beauchamp JES (2020) Interdependence of physical and psychological morbidity among patients with cancer and family caregivers: review of the literature. Psychooncology 29(6):974–989. https://doi.org/10.1002/pon.5382
30. Manne SL, Ostroff JS, Norton TR, Fox K, Goldstein L, Grana G (2006) Cancer-related relationship communication in couples coping with early stage breast cancer. Psychooncology 15(3):234–247. https://doi.org/10.1002/pon.941
31. Manne SL, Kissane D, Zaider T et al (2015) Holding back, intimacy, and psychological and relationship outcomes among couples coping with prostate cancer. J Fam Psychol 29(5):708–719. https://doi.org/10.1037/fam0000096
32. Xu J, Ellington L, Heyman RE, Vadaparampil ST, Reblin M (2020) Money matters: an analysis of advanced cancer couples’ communication about financial concerns. Support Care Cancer 28(5):2239–2246. https://doi.org/10.1007/s00520-019-05045-z
33. Sadigh G, Gallagher K, Obenchain J et al (2019) Pilot feasibility study of an oncology financial navigation program in brain cancer patients. J Am Coll Radiol 16(10):1420–1424. https://doi.org/10.1016/j.jacr.2019.07.014
34. Tanco K, Vidal M, Arthur J et al (2018) Testing the feasibility of using the Edmonton Symptom Assessment System (ESAS) to assess caregiver symptom burden. Palliat Support Care 16(1):14–22. https://doi.org/10.1017/S1478951517000098
35. Zabora J, BrintzenhofeSzoc K, Jacobsen P et al (2001) A new psychosocial screening instrument for use with cancer patients. Psychosomatics 42:241–246
36. Radloff LS (1977) The CES-D scale: a new self-report depression scale for research in the general population. Appl Psychol Meas 1:385–401
37. Hays RD, Bjorner JB, Revicki DA, Spritzer KL (2009) Cell Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. Qual Life Res 18(7):873–880 (PubMed: 19543809)
38. Arden-Close E, Moss-Morris R, Dennison L, Bayne L, Gidron Y (2010) The Couples’ Illness Communication Scale (CICS): development and validation of a measure assessing illness-related couple communication. Br J Health Psychol 15:543–559
39. Kenny DA, Kashy DA, Cook WL (2006) Dyadic data analysis. Guilford Press, New York
40. Fenn KM, Evans SB, McCorkle R et al (2014) Impact of financial burden of cancer on survivors’ quality of life. J Oncol Pract 10(5):332–338. https://doi.org/10.1200/JOP.2013.001322
41. Barbaret C, Delgado-Guay MO, Sanchez S et al (2019) Inequalities in financial distress, symptoms, and quality of life among patients with advanced cancer in France and the U.S. Oncologist 24(8):1121–1127. https://doi.org/10.1634/theoncologist.2018-0353
42. Wheeler SB, Spencer B, Manning ML, Cleo SA, Reeder-Hayes, KE, Sellers JB, Rosenztein DL (2018) Cancer-related financial burden among patients with metastatic breast cancer. J Clin Oncol 36(suppl 30; abstr32). https://doi.org/10.1200/JCO.2018.36.30_suppl.32
43. Lopez G, Milbury K, Chen M, Li Y, Bruera E, Cohen L (2019) Couples’ symptom burden in oncology care: perception of self and the other. Support Care Cancer 27(1):139–145. https://doi.org/10.1007/s00520-018-4298-7
44. Langer SL, Brown JD, Syrjala KL (2009) Intrapsychical and interpersonal consequences of protective buffering among cancer patients and caregivers, Cancer 115(18 Suppl):4311–4325. https://doi.org/10.1002/cncr.24586
45. Manne SL, Norton TR, Ostroff JS, Winkel G, Fox K, Grana G (2007) Protective buffering and psychological distress among couples coping with breast cancer: the moderating role of relationship satisfaction. J Fam Psychol 21(3):380–388. https://doi.org/10.1037/0899-3200.21.3.380
46. Falconer MK, Rusu PP, Bodenmann G (2019) Initial validation of the dyadic coping inventory for financial stress. Stress Health 35(4):367–381. https://doi.org/10.1002/smi.2862
47. Tarnasky AM, Tran GN, Nicolla J, Friedman FAP, Wolf S, Troy JD et al (2021) Mobile application to identify cancer treatment-related financial assistance: results of a randomized controlled trial. J Clin Oncol Pract. https://doi.org/10.1200/OP.20.00757
48. Nipp RD, Lee H, Gorton E et al (2019) Addressing the financial burden of cancer clinical trial participation: longitudinal effects of an equity intervention. Oncologist 24(8):1048–1055. https://doi.org/10.1634/theoncologist.2019-0146

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.