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Distress Screening is Feasible and Acceptable for Family Caregivers at an Oncologic Surgical Center: Evidence from a Mixed-Methods Feasibility Study

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Abstract

OBJECTIVES: Procedures that efficiently identify informal caregivers with supportive care needs and triage them to appropriate resources will reduce caregivers' treatment access barriers. Towards this end, we conducted a feasibility study of a validated electronic distress screening program for cancer caregivers.

SAMPLE AND SETTING: Informal caregivers ($n=17$ [9 female], age $M=59$ [range=36–83]) presenting with a patient to an ambulatory cancer surgery center.

METHODS AND VARIABLES: Caregivers self-reported demographics, completed the distress screener on a tablet computer, and then completed a brief semi-structured interview about their perceptions of the screener.

RESULTS: Caregivers described the screener as straightforward and comprehensive. They frequently endorsed concerns about their self-care needs but were most likely to request information or a referral for patient-focused concerns. Caregivers frequently requested informational resources, but few requested referrals. Referrals generated from the program are likely viably addressed with existing supportive care resources.

IMPLICATIONS FOR NURSING: Brief, caregiver-focused distress screening is perceived positively by caregivers. Caregivers indicated they felt it validated the importance of their role and highlighted the hospital's effort to continually improve care. Given that medical care responsibilities are quickly transferred from nursing to caregivers at ambulatory surgical centers,

this screening program may be particularly beneficial in these contexts to efficiently identify caregivers with concerns and provide a point of entry to remediate these concerns.

Keywords

caregivers; feasibility study; distress screening; supportive care; unmet needs

Caregiving is demanding psychosocially, yet a supportive informal caregiver provides invaluable assistance to patients, helping them adhere to and receive the most benefit from their cancer care (Kissane, 2013). The roughly three million Americans who were caregivers to people with cancer in 2015 comprise relatives, friends, or partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to the patient (National Association for Caregiving [NAC], 2016; NAC & AARP, 2015). As a result of these demands, caregivers are at risk for clinically significant symptoms of depression and anxiety (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Chambers et al., 2013; Janda et al., 2007; Sklenarova et al., 2015) and medical morbidity (Beesley et al., 2011; Buyck et al., 2013; Ji, Zöller, Sundquist, & Sundquist, 2012; Morris et al., 2015; Vitaliano et al., 2002). Despite the need for interventions to support caregivers, and the existence of multiple programs that are successful in doing so (Northouse, Katapodi, Song, Zhang, & Mood, 2010), such services are typically underutilized by caregivers (Applebaum, Farran, Marziliano, Pasternak, & Breitbart, 2014). This underutilization may be due in part to multiple practical and psychological barriers that interfere with caregivers' access to services (Adam, 2000; Applebaum et al., 2014; Morris & Thomas, 2001; Ramirez, Addington-Hall, & Richards, 1998; Shaw et al., 2013). As such, procedures like routine distress screening that efficiently identify caregivers with supportive care needs and triage them to accessible interventions and resources will be critical to overcoming these treatment access barriers.

Despite repeated calls to integrate family-centered support services into cancer care (Kent et al., 2016), most adult oncology practice settings have not established standardized protocols to identify caregivers with greater emotional, social, and practical support needs. Only about one in four caregivers access psychosocial care (Applebaum et al., 2014; Glasdam, Jensen, Madsen, & Rose, 1996), despite documented need (Vanderwerker, Laff, Kadan-Lottick, Mccoll, & Prigerson, 2005) and strong demand for services (Applebaum et al., 2014; Baghi et al., 2007; Dionne-Odom et al., 2018; Nightingale et al., 2016). In fact, distressed caregivers report higher interest in supportive interventions compared to caregivers with lower distress (Nightingale et al., 2016). Among the many barriers that contribute to this notable limited uptake of services, caregivers frequently cite the issues of scheduling difficulty and limited time, lack of knowledge of resources, not wanting to 'bother' the healthcare team, and belief that accessing such care would inappropriately put their needs ahead of the patients' needs (Applebaum et al., 2014; Badr et al., 2016; Shaw et al., 2013; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013).

Among people with cancer, distress screening has been found to be an efficient means to identify individuals with high unmet needs and triage them into the appropriate level of supportive care (Carlson, Groff, Maciejewski, & Bultz, 2010), thereby overcoming many treatment access barriers. Assessing and addressing psychosocial needs have been associated

with important clinical benefits for patients, including reduced distress and fewer hospitalizations, emergency room visits, and number of filled prescriptions (Carlson, Groff, Maciejewski, & Bultz, 2010; Sobel, 2000). As such, the Institute of Medicine (IoM, 2008) and the National Comprehensive Cancer Network (NCCN, 2018) have recognized that screening, referral, and follow-up for psychosocial concerns are critical to ensuring high-quality comprehensive cancer care. However, extant distress screening programs have primarily targeted patients alone, which ignores the reality that psychosocial distress in the cancer context is frequently interrelated between patients and their families (Girgis, Lambert, Johnson, Waller & Currow, 2012; Shaffer, Kim, & Carver, 2016).

As such, developing and implementing a caregiver-focused distress screening program has significant potential to improve quality of care for all those affected by cancer. Beyond addressing the substantial mental and physical health burdens experienced by caregivers, such routine procedures may begin to shift caregivers' and healthcare systems' cultural norms around caring for caregivers—from the exception to a norm. Towards these aims, the authors conducted a feasibility study of CancerSupportSource®-Caregiver, a validated electronic distress screening program designed to address the unique concerns of cancer caregivers (Longacre et al., 2017; Zaleta et al., 2017). The two primary purposes of this study were: (1) to characterize the concerns and preferred responses to concerns identified by caregivers at the time of their family members' ambulatory surgery, and (2) to determine the extent to which caregivers find screening at that time in the care continuum to be acceptable and feasible.

METHOD

Design, Participants, and Setting

To answer primary study aims, both quantitative (e.g., CaregiverSupportSource-Caregiver responses) and qualitative (e.g., interview) data were collected for this mixed-methods feasibility study. Participants were primary, informal caregivers presenting to the Josie Robertson Surgery Center (JRSC) at Memorial Sloan Kettering Cancer Center (MSKCC) with their family member (i.e., the patient) in March 2018, identified by convenience sampling from among the total population of presenting caregivers. JRSC is a first-of-its-kind, free-standing outpatient facility for ambulatory cancer surgery. Given the short-stay nature of procedures performed at JRSC, patients are required to present with a caregiver who: (a) is 18 years of age or older and (b) agrees and is able to fulfill assigned responsibilities during the pre-, intra-, and post-operative phase. The only additional eligibility criterion for this study was comfort speaking and reading English. Only one caregiver participated per patient.

Procedure

Potentially eligible caregivers were approached by the perioperative nurse liaison (CB) and the interviewer (either KMS or SB) during the perioperative nurse liaison's routine rounds through the family waiting room. If the caregiver was comfortable communicating in English, the perioperative nurse liaison provided a brief introduction to the interviewer and study. The purpose of the study was described to caregivers as: MSKCC was interested in

determining ways to better link family caregivers to available services at JRSC and community partners, such as the Cancer Support Community (CSC), and this study was assessing caregivers' opinions of the CancerSupportSource-Caregiver screening process.

No personally identifying information was collected from caregivers, and as such, this study protocol was approved for exempt status under the MSKCC Institutional Review Board. Upon providing verbal agreement to participate, caregivers completed study procedures individually in a private consultation room. Caregivers first completed self-reported demographic information by paper-and-pencil, then completed CancerSupportSource-Caregiver, and last completed a brief semi-structured interview. There was no compensation for participating.

Caregiver Distress Screen

The development and validation of CancerSupportSource-Caregiver among cancer caregivers in the Cancer Support Community (CSC) affiliate support network has been previously published (Longacre et al., 2017; Zaleta et al., 2017), and the program is currently implemented at over 40 of the CSC community-based facilities. This program was based on the CSC's CancerSupportSource-Patient, a web-based distress screening and referral program for people with cancer (Miller, Mullins, Onukwugha, Golant, & Buzaglo, 2014). These programs were developed in accordance with the IoM 2008 guidelines for comprehensive management of psychosocial distress in the cancer context, recognizing that diverse unmet psychosocial needs can have profound effects on the well-being of people with cancer and their families (for review, see Chapter 2, IoM, 2008).

CancerSupportSource-Caregiver asks caregivers to rate their level of concern for 33 different possible problems (see Table 1 for items), and how they would prefer these concerns to be addressed. The screening is completed by an Internet-enabled tablet computer; data entered into screener are encrypted and stored in a secure, HIPAA-compliant database. Responses are not forced to any item; data are missing where participants intentionally or unintentionally do not indicate a response. As the purpose of this study was to naturalistically observe caregivers' use of the screener, researchers did not intervene to limit missing data.

Possible concerns assessed range from problems with caregivers' own self-care needs, own emotional well-being, caregiving tasks, or perceived concerns about the patients' well-being. If a potential concern is rated as of low concern (i.e., "A little" or "Not at all"), caregivers may request pertinent educational materials (i.e., request for information). If a significant concern is endorsed (i.e., "Moderately," "Seriously," or "Very Seriously" concerning problem), caregivers also have the option to request to speak with someone about that need (i.e., receive a referral) and/or receive information. A referral is not automatically generated when a caregiver endorses a significant concern for two reasons: (1) it respects the caregivers' autonomy to have their concerns addressed in the way that they prefer, and (2) it acknowledges that caregivers may be receiving support elsewhere for the concern. Referral sources within MSKCC were designated to address each item (e.g., Chaplaincy for spiritual concerns; Patient Financial Services for fiscal concerns). Regardless of level of concern endorsed, caregivers may also request "No action" be taken for the concern at that time.

Participants who requested information about a concern were provided paper copies by their interviewer of relevant materials from both MSKCC and CSC at the completion of their participation; those who requested a referral were provided with the contact information of the appropriate MSKCC resource from their interviewer at the completion of their participation.

Two scores were calculated from the screening. First, an overall distress score was calculated by summing the level of concern across the 33 items (0=*Not at all* to 4=*Very Seriously*). Scores could range from 0 to 132, with higher scores indicating greater distress. Content validity of this total score has been established (Longacre et al., 2017). Second, a depression risk subscale was calculated by summing scores from four items (see Table 1), with a score of five or greater indicating risk for clinically significant depression (Buzaglo et al., 2014). For those with missing data ($n=3$ for total distress score, $n=1$ for depression risk score), mean imputation was used to adjust for missing responses. Participants who met criteria for depression risk were assessed for imminent self-harm and provided a referral to the MSKCC Counseling Center.

Semi-Structured Qualitative Interviews

Upon completion of CancerSupportSource-Caregiver, the first five participating caregivers completed a brief interview intended to identify any significant problems with the screening or interview process (pilot participant numbers: P1-P5); the subsequent 12 caregivers completed a brief interview regarding perceived acceptability and feasibility of the screening process (acceptability/feasibility participant numbers: AF1-AF12). As such, the pilot participants and acceptability/feasibility participants completed slightly different interviews. Interviews lasted approximately 15 minutes. Semi-structured interview guides were developed (by MSK, SB, and AJA) for both study phases, and interviewers used ad-hoc clarifying and elaborating probes as appropriate. The two interviewers (KMS and SB) who conducted interviews were trained on the interview guides and had prior experience completing qualitative interviews with cancer caregivers. Interviewers had no pre-existing relationships with the participants and there was no follow-up contact between interviewers and participants. Interviewers took comprehensive notes during the interview; interviews were audio-recorded to validate notes as needed, and recordings were destroyed within 48 business hours.

Analysis

Descriptive statistics are presented for caregivers' self-reported demographics and screening responses (mean, median, frequency, and/or range, as appropriate).

The interview notes were reviewed by KMS and AJA using inductive thematic textual analysis, an iterative process of review, interpretation, and consensus discussions (Patton, 2002). The two coders read the field notes and identified important content independently, then shared their independent coding results and collectively generated overarching themes that emerged (Miles, Huberman, & Saldana, 2014). Key exemplary quotations of themes were then extracted.

RESULTS

Sample characteristics are listed in Table 2. The sample was characteristic of the population of primary caregivers presenting to JRSC in 2017, during which time the most commonly reported relationship between the patient and the presenting primary caregiver was spouse/partner, and the median age of patients was 55 (per internal clinic data not shown).

Quantitative Findings

Recruitment and screening completion.—Of the 28 caregivers approached to participate, only three refused (11 percent refusal rate). All three who refused stated the refusal reason of the estimated study time (30 to 45 minutes) was too long. Eight caregivers who initially agreed to participate were not able to be enrolled due to constraints on the interviewers' time at JRSC. As such, 17 caregivers completed the study.

The average time to complete CancerSupportSource-Caregiver was 11.3 minutes (range: 6–18 minutes). Six caregivers had missing data on their screeners. Of the 66 items (i.e., 33 problem areas assessing both level of concern and desired follow-up, if any), three individuals missed one item, two individuals missed three items, and one individual missed 25 items. Missing responses were more common for responses regarding desired follow-up ($n=23$ missing responses) than the rating of the severity of concern ($n=11$).

Distress scores.—A summary of participating caregivers' responses to concerns queried on CancerSupportSource-Caregiver are listed in Table 1. Caregivers on average reported a distress score of 31.1 (SD=26.8, range: 3.7–117). Five caregivers met the depression risk threshold score of five or greater. Sixteen caregivers reported at least one item was of moderate or greater concern ($Mdn=8$, range=1–31 items of moderate concern per person). Items most commonly rated of moderate or greater concern were “The patient's cancer progressing or coming back (recurring)?” ($n=14$), “Worrying about the future and what lies ahead” ($n=9$), “Exercising and being physically active” ($n=8$), and “Keeping up with my own health care needs” ($n=8$).

Requested response to concerns.—A summary of participating caregivers' preferred responses to concerns queried on CancerSupportSource-Caregiver are also listed in Table 1. Ten caregivers requested information for at least one concern area ($Mdn=7.5$, range: 1–14 information requests per person). Concerns for which caregivers most commonly requested information were from patient well-being concerns (“Changes in patient's mood/behavior” $n=6$, “Patient's cancer progressing/recurring” $n=6$, “Patient's pain/discomfort” $n=4$), as well as the concerns of “Exercising and being physically active” ($n=4$) and “Managing side effects” ($n=4$). Five caregivers requested at least one referral for a total of 16 referrals generated ($Mdn=2$, range: 1–6 referrals per person). Referrals were most commonly requested in response to caregiving task concerns ($n=7$) and patient well-being concerns ($n=6$).

Qualitative Findings

Two key themes emerged from the qualitative interviews (see Table 3 for exemplary quotations). First, caregivers described feeling that the screening demonstrated that the hospital acknowledged and appreciated their important role in patients' healthcare, and caregivers appreciated that recognition. Caregivers also described the screening as reinforcing their perception that the hospital is committed to consistently improving healthcare for everyone affected by cancer. Second, caregivers described how the screening provided them with a unique opportunity to talk about their caregiving experience. Caregivers described how their focus was centered on providing care to their family member, and that the screening process helped them to feel permission to consider their own needs by offering space to discuss their challenges as a caregiver. Several caregivers also noted that it was helpful to learn about the many supportive services available to them, both in the hospital and in the community.

Interviews also revealed practical considerations about screening (see Table 4 for quotations). Caregivers acknowledged that they experienced significant stress while waiting through their family member's surgical procedure, and believed that this could be a barrier to screening uptake for some caregivers. In their personal experience, however, they felt it was an "optimal" (AF1–Male [M], age 50s) and "considerate" (AF10–Female [F], 50s) time for the screening, as it served as a distraction technique and coping mechanism. Although most caregivers appreciated the timing of the screening, there was variability in their stated preferences for and perceived drawbacks to various times for completing screening. When directly queried for concerns about the screening process, no caregivers expressed concerns. Two caregivers (AF7–F, 70s; P2–M, 70s), however, expressed appreciation for knowing the confidentiality of the screening and interview data, which was reviewed as part of the verbal consent procedure for study participation.

Interviews also highlighted three modifications that would improve the screening experience. First, two caregivers (AF7–F, 40s; AF9–M, 30s) noted that it was stressful being approached by two individuals in the waiting room, in the context of their loved one being in surgery. Second, two caregivers (P1–M, 60s; P4–F, 60s) discussed they would have liked clarification about the response to concerns options. Although they had significant concerns about several problem areas, they felt they were receiving the support they needed elsewhere. Although they selected the "nothing at this time" response option, they felt "rude" (P4) declining intervention from the institution. Last, although caregivers generally indicated the screening was "simple" (AF3–F, 60s), "user friendly" (AF10–F, 50s), and "straightforward" (AF8–F, 40s), some caregivers indicated difficulty with quantifying responses to the questions—one caregiver stated, "The answer categories are too broad for me to understand. Slightly/moderately.... what's the difference? Questions like managing your loved one's care is broad too. There's so much that goes into that" (AF2–F, 70s). One caregiver also endorsed difficulty responding when questions did not feel applicable, stating the screening was "mostly easy enough, would be easier if [patient's name] was my spouse or my child or we lived together, so it actually was kind of hard... a couple of questions were difficult because we're siblings and not living together" (P4–F, 60s). One caregiver

(AF7–F, 40s) suggested adding an instructions page to introduce the screening, which would be helpful in preempting some of the above listed concerns.

DISCUSSION

From the first study of a comprehensive caregiver-specific distress screening program implemented in a comprehensive cancer center, this study presents evidence of the acceptance, utility, and feasibility of electronic distress screening among caregivers at the time of their family members' ambulatory surgery. Caregivers generally described the screener as straightforward and comprehensive, although important modifications to both the screening process (e.g., adding an instructions page) and study procedure (e.g., approach by one study member) were learned. Participants perceived the screening as a validation of the importance and challenge of their role in patients' healthcare, as well as emblematic of the hospital's mission to continually improve healthcare for all those affected by cancer. Only 30 percent of caregivers requested to speak with someone about a concern, and no service generated more than two referrals, suggesting that supportive care services would not be overwhelmed by full-scale implementation of such a program. Although further study is warranted to understand how this program might ultimately improve caregivers' well-being and overcome common treatment uptake barriers, preliminary evidence is promising that this program is well-received by caregivers and feasible at the patients' point of care.

Although caregivers frequently rated their own self-care needs as significant concerns, they were most likely to request information or a referral for concerns related to the patients' well-being. Prior validation studies among caregivers at community cancer support centers found contrasting findings: although caregivers frequently rated patient well-being issues as significant concerns, they more often requested to speak with someone about their own emotional well-being concerns (Longacre et al., 2017). Caregivers in the present study reflected that, although they had some significant personal self-care concerns, they believed many of these matters (e.g., "Keeping up with my own health care needs") were already being addressed elsewhere, such as by their primary care physician. Findings may reflect the differing contexts where screening occurs: the patients' cancer hospital as the optimal resource to address patient-related concerns versus community support organizations and caregivers' own healthcare providers as optimal resources to address caregivers' personal concerns. Matching caregivers' needs to organizations most suited to provide appropriate services will be important to ensure caregivers' needs are met in the context of already overburdened healthcare systems. However, several caregivers were surprised to learn how many resources were available to them at MSKCC, suggesting the utility of such a distress screening program to link caregivers directly with available resources targeted to their needs. Moreover, this program may have even greater utility within contexts serving populations with more limited access to healthcare services, who may have no other providers to address their personal emotional and self-care needs.

Findings from the current study also quelled a concern faced by the study team prior to completing the feasibility study, namely, that caregivers would generally be unwilling or unable to complete the screening due to distress. Caregivers agreed to participate in this study at a notably higher rate (25 agreed of 28 approached, 89%) than is typical among

cancer caregiver research studies (53 to 58 percent; Kent et al., 2016), with participants reporting a broad range of distress levels. Caregivers also described how other caregivers might be too “overwhelmed” to complete screening in the waiting room, but in their personal experience, they found the screening to be a helpful distraction and coping tool for managing their distress at that time. Although caregivers generally described the waiting period as a good time to complete the screening as a time devoid of caregiving responsibilities, there was some noted variability in caregivers’ preferred time to complete screening. Findings suggest that, although the perioperative period may be an optimal time for most caregivers to complete screening, investigating other options for screening delivery to accommodate caregivers’ differing preferences will be important for ensuring broad uptake of the screening.

Limitations and Future Research

Three primary factors limit the findings from this study. First, qualitative interviews were brief, and therefore the themes identified regarding screening feasibility and acceptability during the perioperative period may not be exhaustive. Additionally, the interviews were not transcribed and we did not utilize qualitative analytics software (e.g., NVivo) to evaluate the narratives. Acknowledging these limitations, brief interviews were utilized for two primary reasons: (1) to limit caregivers’ participation burden during the distressing perioperative time, and (2) to increase the number of caregivers able to participate per day, given the limited window each morning when procedures are conducted. Despite these design considerations, we were unable to enroll eight eligible and potentially interested caregivers, given the limited amount of time available from study staff who donated their time for this project. Future studies will ensure personnel support is available for all eligible and interested participants to enroll. Second, this study was completed at a free-standing surgical facility that serves patients eligible for outpatient procedures (e.g., lumpectomies, prostatectomies), who tend to have non-metastatic disease, often with chance of cancer cure or long-term survival. As such, the experience of a distinct group of caregivers was captured. Future extensions of this work to inpatient surgical and outpatient care facilities, as well as less resourced institutions, where the distress – and need for psychosocial support – may be greater due to caregivers’ more complicated and lengthy caregiving trajectories and patients’ poor prognoses.

Last, as no identifying participant data were collected, data were cross-sectional and there were no data regarding uptake of supportive services. For the next phase of our research, the research team will complete a small-scale randomized controlled trial comparing CancerSupportSource-Caregiver distress screening program with automated referrals to enhanced usual care (i.e., providing caregivers access to resource lists for informational guides and services available at MSKCC). Findings are potentially significant in that: (1) a procedure that effectively connects caregivers to resources will substantively increase the reach of existing, efficacious interventions for caregivers that have been underutilized and narrowly disseminated; and (2) by identifying specific needs and tailoring referrals to those needs, this system may help optimize healthcare provided to caregivers, ultimately reducing service wait times and healthcare costs and increasing health systems’ responsiveness to caregivers’ needs.

Implications for Practice

Nursing care is increasingly patient-family focused. Recognizing the important role caregivers play in surgical recovery supports optimized care in a healthier home environment. Many caregivers perform tasks at home similar to those performed by professional nursing staff (NAC, 2016; NAC & AARP, 2015). This is especially the case at JRSC, where almost all of the patients undergoing prostate or breast surgery will be discharged home with a catheter or drain that the caregiver must demonstrate competency on its maintenance prior to patient discharge. Short-stay and ambulatory surgical centers may particularly benefit from such a measure to routinely identify caregivers with concerns about their care requirements and provide a point of entry to discuss and remediate these concerns. Supporting caregivers promotes the delivery of quality care throughout the patient's recovery and beyond.

Beyond concerns about caregiving responsibilities, caregivers in our study appreciated the opportunity to identify, share, and address their needs related to their own well-being, as well as that of their family member with cancer. In lieu of formal assessment, practitioners can greatly benefit caregivers by acknowledging that caregiving can be challenging, reinforcing that caring for themselves is essential, and providing a list with key informational and supportive care resources available to them (Porter & Dionne-Odom, 2017). Implementing extant validated screening procedures such as CancerSupportSource-Caregiver, however, would help better ensure all caregivers' needs are routinely and comprehensively assessed and addressed.

Conclusion

Routine, comprehensive, and confidential distress screening via CancerSupportSource-Caregiver was acceptable to, and appreciated by, caregivers whose family member was undergoing ambulatory surgery. Issues most frequently rated of significant concern to caregivers did not tend to align with the issues for which caregivers requested information or referrals, which may reflect caregivers meeting their needs in other healthcare settings or a perception that oncology centers exclusively address needs of individuals with cancer. Caregivers were frequently interested in informational resources, and few referrals were generated, suggesting a modest increase in referrals that may be viably addressed with existing resources. Further study will help determine whether such a system that efficiently routes caregivers to the information and resources matching their needs and preferences may improve caregiving burden and caregivers' overall quality of life.

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REFERENCES

- Adam J (2000). Discharge planning of terminally ill patients home from an acute hospital. *International Journal of Palliative Nursing*, 6(7), 338–345. 10.12968/ijpn.2000.6.7.12647 [PubMed: 11309905]

- Applebaum AJ, Farran CJ, Marziliano AM, Pasternak AR, & Breitbart W (2014). Preliminary study of themes of meaning and psychosocial service use among informal cancer caregivers. *Palliative and Supportive Care*, 12(02), 139–148. 10.1017/S1478951513000084 [PubMed: 23919966]
- Badr H, Herbert K, Reckson B, Rainey H, Sallam A, & Gupta V (2016). Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *Journal of Psychosocial Oncology*, 34(4), 336–346. 10.1080/07347332.2016.1195901 [PubMed: 27269579]
- Baghi M, Wagenblast J, Hambek M, Radeloff A, Gstoettner W, Scherzed A, Strebhardt K (2007). Demands on caring relatives of head and neck cancer patients. *The Laryngoscope*, 117(4), 712–716. 10.1097/MLG.0b013e318031d0b4 [PubMed: 17415143]
- Beesley VL, Price MA, Webb PM, Group, A. O. C. S., Study, A. O. C., & Investigators, Q. o. L. S. (2011). Loss of lifestyle: health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Supportive Care in Cancer*, 19(12), 1949–1956. 10.1007/s00520-010-1035-2 [PubMed: 21125296]
- Braun M, Mikulincer M, Rydall A, Walsh A, & Rodin G (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of Clinical Oncology*, 25(30), 4829–4834. doi: 10.1200/JCO.2006.10.0909 [PubMed: 17947732]
- Buyck J-F, Ankri J, Dugravot A, Bonnaud S, Nabi H, Kivimäki M, & Singh-Manoux A (2013). Informal caregiving and the risk for coronary heart disease: the Whitehall II study. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, 68(10), 1316–1323. 10.1093/gerona/glt025
- Buzaglo J, Miller MF, Gayer C, Morris A, Kennedy V, & Golant M (2014). CancerSupportSource: Validating a 13-item web-based distress screening tool in the community. Paper presented at the 19th Annual Conference of the *National Comprehensive Cancer Network*, Hollywood, FL. *Journal of the National Comprehensive Cancer Network*, 12(3), 309.
- Carlson LE, Groff SL, Maciejewski O, & Bultz BD (2010). Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *Journal of Clinical Oncology*, 28(33), 4884–4891. doi: 10.1200/JCO.2009.27.3698 [PubMed: 20940193]
- Chambers SK, Schover L, Nielsen L, Halford K, Clutton S, Gardiner RA, Occhipinti S (2013). Couple distress after localised prostate cancer. *Supportive Care in Cancer*, 21(11), 2967–2976. 10.1007/s00520-013-1868-6 [PubMed: 23756617]
- Dionne-Odom JN, Applebaum AJ, Ornstein KA, Azuero A, Warren PP, Taylor RA, . . . Pisu M. (2018). Participation and interest in support services among family caregivers of older adults with cancer. *Psycho-Oncology*, 27(3), 969–976. 10.1002/pon.4603 [PubMed: 29226997]
- Glasdam S, Jensen AB, Madsen EL, & Rose C (1996). Anxiety and depression in cancer patients' spouses. *Psycho-Oncology*, 5(1), 23–29. 10.1002/(SICI)1099-1611(199603)5:1<23::AID-PON206>3.0.CO;2-H
- Girgis A, Lambert S, Johnson C, Waller A, & Currow D (2012). Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *Journal of Oncology Practice*, 9(4), 197–202. doi: 10.1200/JOP.2012.000690 [PubMed: 23942921]
- Institute of Medicine. (2008). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. In Adler NE & Page AEK (Eds.). Washington (DC).
- Janda M, Steginga S, Langbecker D, Dunn J, Walker D, & Eakin E (2007). Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*, 63(6), 617–623. 10.1016/j.jpsychores.2007.06.018 [PubMed: 18061752]
- Ji J, Zöller B, Sundquist K, & Sundquist J (2012). Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients. *Circulation*, 125(14), 1742–1747. 10.1161/CIRCULATIONAHA.111.057018 [PubMed: 22415143]
- Kent EE, Rowland JH, Northouse L, Litzelman K, Chou WYS, Shelburne N, Huss K (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987–1995. 10.1002/cncr.29939 [PubMed: 26991807]
- Kissane DW (2013). Marriage is as protective as chemotherapy in cancer care. *Journal of Clinical Oncology*, 31(31), 3852–3853. doi:10.1200/JCO.2013.51.5080 [PubMed: 24062396]
- Longacre M, Miller M, Golant M, Kennedy V, Zaleta A, & Buzaglo J (2017). *Psychometric properties of a 47-item distress screening tool for caregivers of cancer patients in a community-based sample*.

Paper presented at the 38th Annual Scientific Session of the Society for Behavioral Medicine, San Diego, CA. *Annals of Behavioral Medicine*, 51(suppl 1), S1893.

- Miles MB, Huberman AM, & Saldana J (2014). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: Sage.
- Miller MF, Mullins CD, Onukwugha E, Golant M, & Buzaglo JS (2014). Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Quality of Life Research*, 23(10), 2855–2863. 10.1007/s11136-014-0742-4 [PubMed: 24966017]
- Morris BA, Thorndike FP, Ritterband LM, Glozier N, Dunn J, & Chambers SK (2015). Sleep disturbance in cancer patients and caregivers who contact telephone-based help services. *Supportive Care in Cancer*, 23(4), 1113–1120. 10.1007/s00520-014-2458-y [PubMed: 25297467]
- Morris SM, & Thomas C (2001). The carer's place in the cancer situation: where does the carer stand in the medical setting? *European Journal of Cancer Care*, 10(2), 87–95. 10.1046/j.1365-2354.2001.00249.x [PubMed: 11829054]
- National Association for Caregiving. (2016). *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. Retrieved from http://www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf
- National Association for Caregiving, & AARP. (2015). *Caregiving in the US*. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- National Comprehensive Cancer Network. (2018). Distress management clinical practice guidelines. *Journal of the National Comprehensive Cancer Network*, 16(7), 795–918. [PubMed: 30006420]
- Nightingale CL, Sterba KR, Tooze JA, Milliron B-J, Tetrick LA, Paek M-S, & Weaver KE (2016). Vulnerable characteristics and interest in wellness programs among head and neck cancer caregivers. *Supportive Care in Cancer*, 24(8), 3437–3445. 10.1007/s00520-016-3160-z [PubMed: 26992407]
- Northouse LL, Katapodi MC, Song L, Zhang L, & Mood DW (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: a Cancer Journal for Clinicians*, 60(5), 317–339. 10.3322/caac.20081 [PubMed: 20709946]
- Patton MQ (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Porter LS, & Dionne-Odom JN (2017). Supporting cancer family caregivers: How can frontline oncology clinicians help? *Cancer*, 123(17), 3212–3215. 10.1002/cncr.30759 [PubMed: 28464219]
- Ramirez A, Addington-Hall J, & Richards M (1998). ABC of palliative care. The carers. *BMJ*, 316(7126), 208–211. [PubMed: 9468691]
- Shaffer KM, Kim Y, & Carver CS (2016). Physical and mental health trajectories of cancer patients and caregivers across the year post-diagnosis: a dyadic investigation. *Psychology & health*, 31(6), 655–674. doi: 10.1080/08870446.2015.1131826 [PubMed: 26680247]
- Shaw J, Harrison J, Young J, Butow P, Sandroussi C, Martin D, & Solomon M (2013). Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Supportive Care in Cancer*, 21(3), 749–756. 10.1007/s00520-012-1575-8 [PubMed: 22933130]
- Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, Hartmann M (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*, 121(9), 1513–1519. 10.1002/cncr.29223 [PubMed: 25677095]
- Sobel DS (2000). The cost-effectiveness of mind-body medicine interventions. *Progress in Brain Research*, 122, 393–412. 10.1016/S0079-6123(08)62153-6 [PubMed: 10737073]
- Vanderwerker LC, Laff RE, Kadan-Lottick NS, McColl S, & Prigerson HG (2005). Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. *Journal of Clinical Oncology*, 23(28), 6899–6907. doi: 10.1200/JCO.2005.01.370 [PubMed: 16129849]
- Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, & Siegler IC (2002). A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic Medicine*, 64(3), 418–435. [PubMed: 12021416]
- Waldron EA, Janke EA, Bechtel CF, Ramirez M, & Cohen A (2013). A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psycho-Oncology*, 22(6), 1200–1207. 10.1002/pon.3118 [PubMed: 22729992]

Zaleta AK, Longacre ML, Miller M, Golant M, Kennedy V, Miller K, & Buzaglo JS (2017). Refining a validated distress screening tool for caregivers of cancer patients in a community-based sample. Poster presented at the 22nd Annual Conference of the National Comprehensive Cancer Network, Orlando, FL. *Journal of the National Comprehensive Cancer Network*, 15(5.5), e-31.

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KNOWLEDGE TRANSLATION

- Brief, caregiver-focused distress screening is perceived by caregivers as a validation of the importance and challenge of their role in the patients' healthcare, as well as emblematic of the hospital's mission to continually improve healthcare for all those affected by cancer.
- Only 5 of 17 caregivers (30 percent) who completed CancerSupportSource®-Caregiver distress screening program requested a service referral for any concern, suggesting that supportive care services would not be overwhelmed by full-scale implementation of such a program.
- Completing screening with caregivers during the patients' perioperative period was feasible: Caregivers described how other caregivers might be too "overwhelmed" to complete screening in the waiting room, but that they personally found the screening to be a helpful distraction and coping tool for managing their distress at that time.

Table 1:

CancerSupportSource-Caregiver Items and Responses (N=17)

Item (e.g., possible concern)	Concern Area	Missing Concern	Missing Response	n Rating Item Moderate concern	n Requesting Information	n Requesting Referral	n Requesting Both
Eating and nutrition	Self-care	1	1	6	2	0	1
Exercising and being physically active	Self-care	0	1	8	4	0	0
Keeping up with my own health care needs	Self-care	0	1	8	3	0	0
Feeling irritable or angry	Emotional well-being	0	1	1	0	0	0
Changes or disruptions in work, school, or home life	Emotional well-being	1	1	4	3	0	0
Feeling sad or depressed *	Emotional well-being	0	0	3	1	0	0
Feeling too tired to do the things I need or want to do *	Emotional well-being	0	0	6	2	0	0
Feeling guilty	Emotional well-being	0	0	3	0	0	0
Feeling nervous or afraid *	Emotional well-being	0	0	6	2	0	0
Intimacy and sexual function	Emotional well-being	0	0	5	1	0	0
Worrying about the future and what lies ahead	Emotional well-being	0	1	9	2	1	0
Feeling lonely or isolated *	Emotional well-being	1	0	3	0	0	0
Relationship problems with the patient	Emotional well-being	0	2	1	1	0	0
Tobacco, alcohol, or other substance use	Emotional well-being	1	0	2	1	0	0
My spirituality, faith, or religion	Emotional well-being	1	1	1	0	0	0
Balancing caregiving with other demands	Emotional well-being	0	1	6	2	1	0
Finding meaning and purpose in life	Caregiving tasks	0	0	2	0	0	0
Talking with the patient's doctors and health care team	Caregiving tasks	2	2	5	1	0	1
Talking with family and friends about the patient's condition	Caregiving tasks	0	1	4	1	0	0
Providing transportation to treatment and appointments	Caregiving tasks	0	0	3	3	0	0
Marking treatment decisions	Caregiving tasks	0	1	3	0	0	0
Coordinating medical care for the patient	Caregiving tasks	0	0	5	2	1	0
Managing household finances	Caregiving tasks	1	1	2	1	1	0
Managing health insurance and medical bills	Caregiving tasks	0	0	3	1	1	0
Managing symptoms or side effects of treatment (nausea, swelling, etc.)	Caregiving tasks	0	1	6	4	0	1
Providing physical or medical care to the patient	Caregiving tasks	0	1	4	3	0	1

Item (e.g., possible concern)	Concern Area	Missing Concern	Missing Response	n Rating Item Moderate concern	n Requesting Information	n Requesting Referral	n Requesting Both [‡]
Providing emotional support to the patient	Caregiving tasks	1	0	6	2	1	0
The patient's eating and nutrition	Patient well-being	0	0	5	3	2	0
Changes in the patient's mood or behavior	Patient well-being	0	1	6	6	0	0
Changes in the patient's memory and/or thinking	Patient well-being	1	1	1	2	0	0
The patient's pain and/or physical discomfort	Patient well-being	1	0	6	4	2	0
The patient's sleep problems	Patient well-being	0	1	3	3	1	0
The patient's cancer progressing or coming back (recurring)	Patient well-being	0	3	14	6	1	0

* Indicates item from Depression Risk subscale;

[‡]“Requesting Both,” refers to the number of caregivers (n) requesting informational materials and a referral.

Table 2.Self-reported Demographics of Participating Caregivers (*N*=17)

	N (%)	M (range)
Age (years)	-	59 (36–83)
Gender		
Male	8 (47%)	-
Female	9 (53%)	-
Education		
High school graduate/GED	1 (6%)	-
Some college/vocational school	2 (12%)	-
College graduate	5 (29%)	-
Some graduate school or more	9 (53%)	-
Relationship to Patient		
Spouse/partner	13 (76%)	-
Parent/parent-in-law	1 (6%)	-
Sibling/sibling-in-law	2 (12%)	-
Adult child	1 (6%)	-
Patients' Cancer Diagnoses		
Breast	9 (53%)	-
Prostate	7 (41%)	-
Thyroid	1 (6%)	-
Comfort with iPad		
Not at all	0 (0%)	-
Somewhat	2 (12%)	-
Very much	8 (47%)	-
Completely	7 (41%)	-

Table 3.Interview Themes and Exemplary Quotations of Participating Caregivers (*N*=17)

Theme	Quotation
Screener shows the hospital cares about caregivers	"It tells me the hospital cares." (P1–M, 60s)
	"Shows you're really concerned about our feelings—the caregivers and families." (P2–M, 70s)
	"This shows that the hospital cares for the family. It's nice." (AF3–F, 60s)
	"It shows you care about patients' and caregivers' best interests and that you want to improve care... Caregivers can help make your job easier, they help do things for the patients, so it's helpful to get everyone—getting their oars all in the same direction." (AF11–M, 60s)
	"Caregivers help the clinicians with patient care, and this screening helps the caregivers." (AF12–M, 50s)
Screening as an opening to talk about caregiving experience and needs	"Appreciate the permission to explain what's going on. Shows you're really concerned about our feelings—the caregivers and families. Makes me feel like you're very conscious of families' experiences." (P3–F, 60s)
	"I liked that it brought up things in my mind that I haven't been able to verbalize to others." (AF7–F, 40s)
	"I completed this so I had someone to talk to since my family and friends haven't been through this... I was able to get things off my chest and it helped me to calm the butterflies in my stomach." (AF9–M, 30s)
	"People generally don't like asking for help, especially when they're thinking about someone else. It's important to reach out because people's needs may not be met... I have no major concerns, but it would really help if someone did have concerns. It could start the conversation easily because that can be intimidating for some people." (AF10–F, 50s)

Note. Participant numbers: P# refers to a pilot participant (*n*=5), AF# refers to an acceptability/feasibility participant (*n*=12); M= male, F= female

Table 4.
Quotations Exemplifying Caregivers' Varied Preferences about Timing of Distress Screening

Timing Consideration	Quotation
Waiting room is stressful time, with both benefits and drawbacks for screening	"There were no distractions. This really helped to pass the time.... No disadvantages for myself, but I could see for an anxious person this might be too much." (AF8-F, 40s)
	"Others might be too emotionally exhausted. This was a good time for me." (AF3-F, 60s)
	"It kept me busy so it was a good time. I helped me to confront these emotions head on." (AF7-F, 40s)
	"This was a good time because it took my mind off of worrying about my wife." (AF12-M, 50s)
Earlier in the cancer trajectory	"I would want to do this earlier in her care. I think it would be better to know about this option sooner." (AF4-M, 40s)
After day of surgery	"After discharge- right now all my thoughts are with my wife... I didn't want to miss anything they may need me for with my wife" (AF11-M, 60s)
Downsides of screening outside waiting time	"If this was asked to be done at home I would be too focused on <i>[patient's name]</i> to do it." (AF3-F, 60s)
	"If this was done at another time, I wouldn't give true answers since I'd be focused on my wife." (AF12-M, 50s)
	"I dread seeing 'MSK' [<i>Memorial Sloan Kettering Cancer Center</i>] in my email. I would really not want more emails from MSK so I would not have wanted to get this through the portal." (AF10-F, 50s)
	"I dread seeing '[HOSPITAL]' in my email. I would really not want more emails from [HOSPITAL] so I would not have wanted to get this through the portal." (AF10-F, 50s)

Note. Participant numbers: P# refers to a pilot participant ($n=5$), AF# refers to an acceptability/feasibility participant ($n=12$); M= male, F= female.