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Communication with children about a parent's advanced cancer and measures of parental anxiety and depression: a cross-sectional mixed-methods study

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Abstract

Purpose—Parents with advanced cancer are faced with difficult decision-making about communication about their illness with their children. The objectives of this study were to describe how parents communicated with their children about advanced cancer and to explore associations between communication and parental depression and anxiety.

Methods—This was a cross-sectional, mixed-methods study of 42 patients with stage IV solid tumor malignancies who had at least one child less than 18 years of age. Participants completed a semi-structured interview and the Hospital Anxiety and Depression Scale (HADS). We used multiple linear regression to evaluate the association between extent of communication and HADS Anxiety and Depression scores. Interview data were analyzed using standard qualitative content and thematic techniques and triangulated with survey data.

Results—Higher HADS Anxiety scores, but not HADS Depression scores, were cross-sectionally associated with greater extent of parental communication ($p=0.003$), even when controlling for performance status and children's ages. In qualitative analyses, parents who acknowledged the terminal nature of their illness or experienced higher symptom burden were

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more likely to report they also communicated more extensively with children. A third of parents (n=14, 33%) described difficulty with illness-related communication with their children.

Conclusions—In this pilot study, parents with advanced cancer who reported more illness-related communication with their children also reported more symptoms of general anxiety. Future interventions should address psychological distress relevant to parenting and further assess how parental communication may be linked to parental mood symptoms.

Keywords

Cancer; Neoplasm; Parent; Child; Communication

Background

Cancer impacts approximately 1.6 million parents with dependent children living at home in the United States (US) [1]. It is a leading cause of death in the US for individuals in their prime parenting years, resulting in more than 20% of deaths in persons aged 20-54 [2]. Recent research findings corroborate clinical knowledge that among adults with cancer, parents with dependent children experience greater psychological distress compared to non-parents [3].

Among parents with cancer, individuals with advanced, incurable illness face unique challenges that affect their psychological functioning. A primary concern for these parents is communication with their children about the nature of their illness [4,5]. Concerns about communication include determining when to talk with children, the best ways to communicate emotionally-charged information, and how much information to share, particularly related to prognosis [6–13]. Despite parents' concerns, many studies of bereaved children demonstrate the beneficial impact of parent-child communication for children's grieving and coping [14–16].

Concerns about how to share information with dependent children are a potential source of psychological distress for parents with cancer. Conversely, parental distress may influence how parents perceive their communication decisions. A qualitative study of the psychosocial needs of parents with advanced cancer by Turner et al. found that parents' distress about their diagnosis was compounded by insufficient communication guidance or resources on such topics [4]. As Turner's results suggest, parents desire professional guidance about illness-related communication with their children, and there are numerous opportunities for health care providers to facilitate parent-child communication. Several communication guidelines for parents and clinicians exist [5,17,18]. However, there is little research on how parents with advanced cancer actually communicate about their illness with children and how communication may be related to parental psychological distress.

Most of the existing research regarding parent-child communication about cancer does not address the needs of parents with advanced illness. Most qualitative studies on parental cancer and communication focus on the experiences of parents with non-terminal illness [6,7,11–13,19]. Studies that do include parents with advanced cancer primarily examine the psychological impact on the children [9,20–23]. Given the high levels of depression and

anxiety experienced by parents with advanced cancer [24], further research is needed to evaluate the relationship between parental distress and communication with children. Therefore, the objectives of this research study were to describe how parents with advanced cancer discuss their illness with their children and to explore associations between parental report of illness-related communication with children and parental psychological distress as measured by the Hospital Anxiety and Depression Scale (HADS).

Methods

Setting

This is a secondary analysis of an existing dataset from a single-center, mixed-methods, observational study of patients with metastatic cancer who had dependent children [24,25]. The UNC Institutional Review Board reviewed and approved the study. Assessments were conducted between May 2013 and April 2014.

Participant identification and recruitment

Patients were eligible if they were at least 18 years of age, spoke English or Spanish, had a diagnosis of a stage IV solid tumor malignancy, had at least one dependent biologic or adopted child less than 18 years old, and had adequate stamina to complete study measures. Patients were excluded if they were unable to complete self-report instruments due to illiteracy or cognitive impairment.

Semi-structured interview

Forty-two parents participated in an in-depth, semi-structured interview addressing illness-related communication with children, coping with advanced cancer, parenting and family concerns, and how parental considerations influenced treatment decision-making. Details regarding these interviews have been published previously [25]. Interviews were digitally recorded and transcribed for analysis using qualitative analysis software (NVivo version 10, QSR International, Victoria, Australia).

Study measures

Symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS). The HADS is a well-established, 14-item self-administered scale with two 7-item subscales for anxiety and depression. Items are rated on a four-point scale with a range of 0–21 for each subscale. Scores >8 on each HADS subscale are typically considered clinically significant [26]. Parenting concerns were measured with the Parenting Concerns Questionnaire (PCQ), a 15-item, self-administered assessment developed for cancer patients. The PCQ has three subscales on a five-point scale that address the emotional and practical impact of illness on children and concerns about the co-parent. Higher scores indicate greater parenting concerns [27]. Functional status was measured by the interviewer-administered Eastern Cooperative Oncology Group (ECOG) performance status scale. Scores range from 0–4 with higher scores reflecting worse functional status [28]. Social support was assessed using the self-administered Medical Outcomes Study (MOS) Social Support Survey. Scores are calculated by averaging items and transforming to a 100-point scale. Higher scores indicate greater social support [29].

Qualitative analyses

This analysis focused on participant responses to questions about illness-related communication with their children (Table 1). Qualitative analysis utilized content and thematic techniques [30,31]. Three authors (CEH, JMY, EMP) reviewed interview transcripts line by line to begin the coding process. Coders independently assigned inductive descriptive codes using the participants' own language when possible. At joint meetings thematic categories were created from groups of related codes to determine the final code structure. The final code structure was re-applied to the transcripts by the authors independently, then differences were discussed at subsequent meetings and resolved through group consensus [32]. The interview codes were condensed into categories, and themes were derived from organizing these categories into conceptual domains.

We further reviewed all interview transcripts to categorize the extent of illness-related communication with children. We separated the extent of communication into three distinctive groups: "Minimal," "Partial," and "Full." Table 2 provides representative quotes describing extent of communication. The "Minimal" category includes parents who communicated nothing or very little with children about their illness. Participants in this category restricted the information they shared with children, only telling them that their parent was sick or simply needed medicine. Included in this category were parents of children too young to comprehend their parents' illness. The "Partial" category includes parents who told children of their illness and communicated information about their treatment, in varying degrees of detail. Parents in this category did not communicate any prognostic information to their children. Parents in the "Full" category discussed their life-limiting prognosis with their children.

Statistical analyses

Descriptive statistics were used to characterize the study sample. Summary statistics were calculated for all participants together and for the three communication subgroups. Bivariable analyses using one-way ANOVAs were used to explore relationships between extent of communication and measures of psychological distress. Multiple linear regression models using communication as a class variable were fit to evaluate the associations between communication with children and HADS Anxiety and Depression scores. In separate models, ECOG performance status, mean children's age, youngest child's age, PCQ score, or social support status score were included as covariates. These variables were also tested in combination but, due to the small sample size, we only report on the models with a single covariate. Results of these models did not differ significantly; therefore, analyses including ECOG score are reported, as this was the strongest illness-related predictor of HADS Anxiety and Depression scores. All analyses were performed using STATA version 14 (StataCorp LP; College Station, TX).

Results

Sample characteristics

Demographic and illness characteristics of the study population are shown in Table 3. Participants were predominantly female (67%) with a mean age of 44 years (range, 21–63)

and had an average of two children. Mean age of the youngest child was 10 years (range, 1–17). The most common diagnosis was breast cancer (n=11, 26%). Mean duration of metastatic disease was 17 months (range, 1–76). Nearly half of participants (n=18, 43%) had an ECOG performance status of 1, reporting that they were fully ambulatory and capable of light activities. Slightly fewer (n=17, 40%) had a performance status of 2 or greater, indicating greater reliance on others for care.

Mean score for the HADS Anxiety subscale was 8.5 (standard deviation, SD, 4.2), indicating clinically significant anxiety. Mean score for the HADS Depression subscale was 6.1 (SD, 4.5), below the threshold of clinical significance. Seven parents (17%) communicated minimal information about their illness, 13 (31%) engaged in partial illness-related communication, and 22 (52%) participated in full communication about their illness and prognosis with their children.

Associations between HADS scores, illness-related communication, and other variables

In bivariable analyses, HADS scores were associated with extent of illness-related communication, ECOG scores, current receipt of anti-neoplastic treatment, social support scores, and parenting concerns scores. Higher HADS Anxiety subscale scores were most strongly associated with greater extent of communication ($p<0.0001$) and higher ECOG scores ($p<0.0001$). Higher HADS Depression scores were most strongly associated with higher ECOG scores ($p<0.0001$) and current receipt of anti-neoplastic treatment ($p=0.048$). In unadjusted analyses for each increase in extent of communication, HADS Anxiety scores increased by 3 points and HADS Depression scores rose by 2 points (Table 4).

More extensive communication was significantly associated with older age of youngest child ($p=0.0013$). Communication was not significantly associated with the following variables: ECOG performance status, gender, race, marital status, income, education, number of children, mean age of children, cancer type, duration of metastatic illness, current receipt of anti-neoplastic treatment, parenting concerns scores, or social support scores.

After controlling for ECOG scores, illness-related communication remained significantly associated with HADS Anxiety scores but not HADS Depression scores (Figure 1). Compared to parents who communicated minimally with children about their illness, parents who had partial discussion about their illness had higher HADS Anxiety scores (4.1 versus 7.6, Table 4). Parents who communicated with children fully about their illness, including prognosis and the possibility of death, reported the highest levels of anxiety (10.4) with mean scores that exceed the clinical screening threshold. Associations between greater illness-related communication and higher HADS Anxiety scores were also significant when controlling for mean age of children or age of youngest child.

Parental perceptions of communication decisions

Our qualitative data provide context to help understand the relationship between more extensive communication with children and higher anxiety (Table 5). Parents who told children of their poor prognosis first understood the possibility of their own death. Many parents who did not share prognostic information with children felt like their death was neither imminent nor likely. As one father with adenocarcinoma explained, “I think they [his

children] know that it's a pretty bad cancer and they can tell that it's took quite a toll on me, but they're like me, they believe I'm going to beat it."

Parents who described greater illness burden or physical impairment in their interview had more openly discussed their illness and prognosis with children to explain changes in their home or functioning. As a mother with metastatic breast cancer and four children noted, "adjustments have to be made and I don't have as much energy or stuff like that, so they need to be able to understand that." Among parents who shared detailed illness or prognostic information with children, acute disruptions in home routine due to cancer treatment were frequently cited as the motivation for increased communication. For many other parents, evidence of disease progression during scans or changes in anti-neoplastic regimens prompted discussions with children. Similarly, unexpected hospitalizations or dramatic deteriorations in physical functioning led to parental disclosures of illness or prognosis. For parents in these circumstances, illness-related communication often felt obligatory. A father with adolescent children and brain metastases noted, "Because of the stroke, I went into the hospital so they knew something was askew immediately."

Roughly one third of parents in this sample expressed that communication with children about their illness and/or prognosis was a source of distress. These parents noted particular difficulty talking with their children about the possibility of dying, or they described uncertainty about whether they had communicated appropriately. Parents with very young children struggled with whether or how to discuss abstract concepts such as death. Some parents of older adolescents reported that their children evaded illness-related communication. A mother with non-small cell lung carcinoma who believed that her sixteen-year-old daughter understood the serious nature of her illness described, "She's not willing to discuss it, and I tried for the first year and a half to two years to discuss it with her ... but she was staunchly opposed and didn't want anything to do with any conversation about it and would panic." Other parents described difficulty communicating with children because of the perceived emotional distress it caused their children or because they felt that communication would violate their parental instincts to protect their children from harm. A mother with a ten-year-old son and appendiceal cancer stated, "I don't think I'm able to talk to him about what I'm going through because he sees all my struggles every day, and I cry. I don't think he understands."

Conclusions

Parents with advanced cancer are a subset of the cancer population at risk for high psychological distress. For parents in this study, extent of illness-related communication with their children were related to their overall levels of anxiety but not depression. Parental anxiety was also related to illness burden, parenting concerns, and social support. While many factors contribute to distress in parents with advanced cancer, parent-child communication is a concern that is particularly suited for intervention. Many health care professionals encourage parents to be open and forthcoming when communicating with children about their illness [15,33–35]. However, given that parental psychological health greatly affects the entire family unit [36,37], the issue of parental distress and communication with their children is of particular importance.

There are several possible reasons for the relationship between increased parental anxiety and illness-related communication with children. In this study, parents who communicated more fully with children understood the likelihood of their early mortality and reasoned that their death was imminent enough to justify discussing prognostic information with their children. Parents who openly communicated with children may have reported higher anxiety because they more fully recognized their prognosis. The literature addressing the relationship between prognostic awareness and mood symptoms in patients with advanced cancer is mixed, with some studies identifying a positive association between prognostic understanding and anxiety [38,39] and other studies demonstrating higher mood symptoms in patients who report uncertainty, unawareness, or denial about their prognosis [40].

Our analysis also showed that a number of participants described their illness burden and physical impairment, both associated with psychological distress [41,42], as reasons that they discussed their illness and prognosis more fully with children. Although we included functional status – a powerful predictor of prognosis and mood [43] – as a covariate in our analysis, this alone does not fully account for the severity of illness experienced by participants. Physical changes (such as reduced stamina) or changes in treatment due to disease progression prompted some parents to disclose more information about their cancer with children to help contextualize the changes in their appearance, functioning, or daily routine (Table 5). In contrast, participants experiencing minimal functional decline, without obvious physical changes or treatment prompting such conversations, may have felt less compelled to disclose the life-limiting nature of their illness to their children.

A third compelling, albeit less common, contributor to the relationship between parental anxiety and communication was the difficult decision-making related to discussing their illness with their children. Prior research suggests that parents with advanced cancer struggle with and desire guidance about how to discuss their illness with children [4]. For a subset of parents in this study, concerns about how to initiate or continue discussions about their illness and prognosis were a unique source of distress. While health care professionals now almost universally recommend open communication about parental illness, offering encouragement without additional supportive care and guidance may leave some parents to feel accountable yet unprepared for this experience, thus worsening anxiety. Although our pilot study does not establish causality, these results suggest that a subset of parents identify prognostic communication with children as a contributor to their distress.

Despite the association found in this study between parent-child communication and anxiety, the findings should not be interpreted to suggest that parents should avoid communicating with their children to decrease parental anxiety. Instead, this study underscores the unique stressors that parents with advanced cancer experience and the need for increased psychosocial support for them and their families. Psychosocial interventions could provide communication guidance and expand supportive care for patients and their children, thereby diffusing the responsibility for illness-related communication. Clinical services such as the Parenting at A Challenging Time (PACT) program at Massachusetts General Hospital provide psycho-educational support, including communication guidance, for parents with cancer [17]. The PACT program or similar programs could serve as an educational model for health care providers to promote parent-child communication. Tailored interventions to

assist parents with illness-related communication are particularly important because research suggests that parents with cancer underestimate the degree of psychological distress experienced by their children [20,44,45] and that especially during latency-age years, children may not spontaneously disclose misperceptions about their parent's illness or treatment [44]. Health care providers, particularly those in oncology and palliative care, are well-positioned to intervene by providing communication guidance for parents with cancer. Parents with cancer would likely benefit from their health care providers recognizing and acknowledging the challenges of parenting with advanced cancer, particularly in regard to illness-related communication with their children.

There are several limitations to this study, including the relatively small sample size from a single institution that only allowed us to control for single covariates in our modeling. Although we examined the combined effects of all covariates, we only report the results of models with individual covariates due to the small sample size. While the results did not significantly differ with a full multivariable model, additional potentially significant associations with demographic or illness variables – such as ethnic and cultural background, duration of illness, and family functioning – could be better accounted for with a larger study population. The cross-sectional nature of this study suggests an association and not causality; furthermore, the HADS is a general measure of anxiety and depression and therefore cannot directly relate psychological symptoms to parenting or concerns about children.

Future research studies are needed to better understand the association between illness-related communication with children and parental mental health outcomes. Inquiries could include longitudinal assessment of parental distress, as parents engage in discussions with children as their illness progresses. More precise measurement of parents' mood symptoms prior to such discussions with children, as well as measurement of anxiety regarding communication, may help to further clarify the relationship between parental anxiety and illness-related communication with children. Research to expand knowledge on parent-child communication about cancer should involve children of the ill parent as well as healthy co-parents. Future studies of parents, co-parents, and their children to assess experiences of all family members would provide a more comprehensive understanding of how parent-child communication influences outcomes for individuals, co-parent dyads, and families. Because parenting is a reciprocal relationship with children (and often with co-parents), this research could be used to inform communication interventions for family units, not only for ill parents.

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References

1. Weaver KE, Rowland JH, Alfano CM, et al. Parental cancer and the family: A population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer*. 2010; 116:4395–4401. [PubMed: 20586037]
2. Heron M. Deaths: Leading causes for 2012. *NVSS*. 2015; 64:1. http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_10.pdf (Last accessed September 28, 2016).
3. Nilsson ME, Maciejewski PK, Zhang B, et al. Mental health, treatment preferences, advance care planning, and location and quality of death in advanced cancer patients with dependent children. *Cancer*. 2009; 115:399–401. [PubMed: 19110677]
4. Turner J, Clavarino A, Yates P, et al. Development of a resource for parents with advanced cancer: What do parents want? *Palliat Support Care*. 2007; 5:135–145. [PubMed: 17578064]
5. Muriel AC, Rauch PK. Suggestions for patients on how to talk with children about a parent's cancer. *J Support Oncol*. 2003; 1:143–145. [PubMed: 15352659]
6. Elmberger E, Bolund C, Lutzen K. Transforming the exhausting to energizing process of being a good parent in the face of cancer. *Health Care Women Int*. 2000; 21:485–499. [PubMed: 11235281]
7. Helseth S, Ulfsaet N. Parenting experiences during cancer. *J Adv Nursing*. 2005; 52:38–46.
8. Turner J, Kelly B, Swanson C, et al. Psychosocial impact of newly diagnosed advanced breast cancer. *Psycho-Oncology*. 2005; 14:396–407. [PubMed: 15386758]
9. Northouse, LL., Mellon, S., Harden, J., et al. Long-term effects of cancer on families of adult cancer survivors. In: Miller, SM.Bowen, DJ.Croyle, RT., Rowland, JH., editors. *Handbook of Cancer Control and Behavioral Science*. Washington, D.C: American Psychological Association Press; 2008. p. 467-485.
10. Semple CJ, McCance T. Parents' experience of cancer who have young children: A literature review. *Cancer Nurs*. 2010; 33:110–118. [PubMed: 20142737]
11. Stiffler D, Haase J, Hosei B, et al. Parenting experiences with adolescent daughters when mothers have breast cancer. *Oncol Nurs Forum*. 2008; 35:113–120. [PubMed: 18192160]
12. Davis Kirsch SE, Brandt PA, Lewis FM. Making the most of the moment: when a child's mother has breast cancer. *Cancer Nurs*. 2003; 26:47–54. [PubMed: 12556712]
13. Billhult A, Segesten K, Strength of motherhood. Non-recurrent breast cancer as experienced by mothers with dependent children. *Scand J Caring Sci*. 2003; 17:122–128. [PubMed: 12753512]
14. Kennedy VL, Williams ML. Information and communication when a parent has advanced cancer. *J Affect Disord*. 2009; 114:149–155. [PubMed: 18684513]
15. Rosenheim E, Reicher R. Informing children about a parent's terminal illness. *J Child Psychol Psychiatry*. 1985; 26:995–998. [PubMed: 4066821]
16. Huizinga GA, Visser A, van der Graaf WTA, et al. The quality of communication between parents and adolescent children in the case of parental cancer. *Ann Oncol*. 2005; 16:1956–1961. [PubMed: 16143592]
17. Marjorie, E. Korff PACT Program. <http://www.mghpact.org/> (Last accessed September 28, 2016)
18. Rauch PK, Muriel AC, Cassem NH. Parents with cancer: Who's looking after the children? *J Clin Oncol*. 2002; 20:4399–4402. [PubMed: 12409342]
19. Hymovich DP. Child-rearing concerns of parents with cancer. *Oncol Nurs Forum*. 1993; 20:1355–1360. [PubMed: 8265439]
20. Visser A, Huizinga GA, Van der Graaf WTA, et al. The impact of parental cancer on children and the family: A review of the literature. *Cancer Treat Rev*. 2004; 30:683–694. [PubMed: 15541578]
21. Grenklo TB, Kreicbergs UC, Valdimarsdottir UA, et al. Communication and trust in the care provided to a dying parent: A nationwide study of cancer-bereaved youths. *J Clin Oncol*. 2013; 31:2886–2894. [PubMed: 23857973]
22. Leedham B, Meyerowitz BE. Responses to parental cancer: A clinical perspective. *J Clin Psychol Med Settings*. 1999; 6:441–461.
23. Huizinga GA, Visser A, Van der Graaf WTA, et al. Stress response symptoms in adolescent and young adult children of parents diagnosed with cancer. *Eur J Cancer*. 2005; 41:288–295. [PubMed: 15661555]

24. Park EM, Deal AM, Check DK, et al. Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psychooncology*. 2016; 25:942–948. [PubMed: 26282575]
25. Park EM, Check DK, Song MK, et al. Parenting while living with advanced cancer: A qualitative study. *Palliat Med*. 2016 Epub ahead of print.
26. Bjellanda I, Dahlb AA, Haug TT, et al. The validity of the hospital anxiety and depression scale: An updated literature review. *J Psychosom Res*. 2002; 52:69–77. [PubMed: 11832252]
27. Muriel AC, Moore CW, Baer L, et al. Measuring psychosocial distress and parenting concerns among adults with cancer: The parenting concerns questionnaire. *Cancer*. 2011; 118:5671–5678.
28. Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol*. 1982; 5:649–655. [PubMed: 7165009]
29. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991; 32:705–714. [PubMed: 2035047]
30. Hewitt-Taylor J. Use of constant comparative analysis in qualitative research. *Nurs Stand*. 2001; 15:39–42.
31. Sandelowski M. Qualitative analysis: what it is and how to begin. *Research in nursing & health*. 1995; 18:371–375. [PubMed: 7624531]
32. Denzin, NK., Lincoln, YS. *The SAGE handbook of qualitative research*. 4th. Thousand Oaks, CA: SAGE; 2011.
33. Siegel K, Mesagno FP, Christ G. A prevention program for bereaved children. *Am J Orthopsychiatry*. 1990; 60:168–175. [PubMed: 2343885]
34. Russell KS, Rauch PK. Parenting with cancer I: Developmental perspective, communication, and coping. *Adv Exp Med Biol*. 2012; 732:131–140. [PubMed: 22210257]
35. Rauch, PK., Muriel, AC. *Raising an emotionally healthy child when a parent is sick*. New York, NY: McGraw-Hill Professional Publishing; 2005.
36. Hoke LA. Psychosocial adjustment in children of mothers with breast cancer. *PsychoOncology*. 2001; 10:361–369. [PubMed: 11536414]
37. Beck TC. Maternal depression and child behaviour problems: A meta-analysis. *J Adv Nursing*. 1999; 29:623–629.
38. El-Jawahri A, Traeger L, Park ER, et al. Associations among prognostic understanding, quality of life, and mood in patients with advanced cancer. *Cancer*. 2014; 120:278–285. [PubMed: 24122784]
39. El-Jawahri A, Traeger L, Kuzmuk K, et al. Prognostic understanding, quality of life and mood in patients undergoing hematopoietic stem cell transplantation. *Biol Blood Marrow Transplant*. 2015; 50:1119–1124.
40. Chan WC. Being aware of the prognosis: How does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context. *Palliat Med*. 2011; 14:997–1003.
41. Adler, NE., Page, AEK., editors. *Cancer Care for the Whole Patient*. Washington, DC: National Academies Press; The psychosocial needs of cancer patients: meeting psychosocial health needs; p. 23–49.
42. Salvo N, Zeng L, Zhang L, et al. Frequency of reporting and predictive factors for anxiety and depression in patients with advanced cancer. *Clin Oncol*. 2012; 24:139–148.
43. Glare P, Sinclair C, Downing M, et al. Predicting survival in patients with advanced disease. *Eur J Cancer*. 2008; 44:1146–1156. [PubMed: 18394880]
44. Christ GH, Siegel K, Freund B, et al. Impact of parental terminal cancer on latency age children. *Amer J Orthopsychiat*. 1993; 63:417–25. [PubMed: 8372908]
45. Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer: Parents' and children's perspectives. *Cancer*. 1996; 77:1409–18. [PubMed: 8608523]

Figure 1.
HADS Depression and Anxiety Scores by Extent of Communication

Table 1

Interview Questions on Illness-Related Communication

Do your children know that you have advanced cancer?
What do you think they understand about that?
How did they find out?
How did you know what to tell them?
What has been the most difficult part about talking with your children?
Did you have any guidance from anyone about how to approach this topic with your kids?
How have you kept your kids up to date as to what is happening?
Do you wish you had had more guidance from your doctors or other health care providers about how to talk about your cancer with your kids?
What kinds of guidance would have been helpful?

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Table 2

Sample Quotes Describing Extent of Communication with Children

Minimal Communication	“I’m just sick, that’s all I say, I don’t get into it. I’m just like ‘I’m sick.’”
	“I have hope. ... that’s the reason why I don’t involve my kids in this. They don’t know that I have cancer. I just tell them daddy’s taking some strong drugs.”
	“We never told him how I have cancer, they just know that I’m sick.”
Partial Communication	“They know that I have cancer ... that it was breast cancer ... that it went to my back, and that’s why I take pain medication ... that’s pretty much what they know. They don’t know what stage IV is ... I don’t want my daughter ... to google stage IV cancer, so we don’t use that word or terminally ill or metastatic or anything like that. ... She’s never asked me, are you gonna die from this.”
	“I’m educating my kids on it, but I haven’t told them how bad it is ... but they do know I have cancer.”
Full Communication	“... from the very beginning they’ve known that it was melanoma. We told them it was stage IV, that we did not know what was going to happen, that we were praying that I could get treatment ... but that we just didn’t know. So they do know the severity of it. They know that I might not make it.”
	“That I could die, they understand that. They’ve been told that this might not work and all that.”
	“They know everything that’s going on, when I take a scan, when I tell people my prognosis ... I make sure my kids be aware of what’s going on, I explain it to them ... whether there’s a new spot or old spots are gone or I start a new treatment, everything, I break it down and let them know what’s going on.”

Table 3

Participant Demographic and Illness Characteristics

Characteristic	Total sample (N = 42)	
	N	Mean (SD) or %
Age, years	42	43.9 (8.9)
Female gender	28	67
Caucasian race	30	71
Married/partnered	35	83
Household income \$50,000	20	49
College graduate	20	48
Number of children	42	2.1 (1.1)
Age of children < 18	42	11.5 (4.0)
Primary cancer site		
Breast	11	26
Melanoma	6	14
Colorectal	5	12
Other	20	48
Months since metastatic diagnosis	42	17.3 (18.4)
Metastatic cancer at diagnosis	20	48
Current anti-neoplastic treatment	37	88
ECOG functional status		
0	7	17
1	18	43
2	9	21
3-4	8	19
PCQ	42	2.3 (0.9)
HADS Depression	41	6.1 (4.5)
HADS Anxiety	42	8.5 (4.2)
MOS	40	75.2 (22.1)

Abbreviations: SD = Standard Deviation; ECOG = Eastern Cooperative Oncology Group Performance Status Scale (range 0–4, higher scores indicate worse performance status); PCQ = Parenting Concerns Questionnaire (range 1–5, higher scores indicate increased parenting concerns); HADS = Hospital Anxiety and Depression Scale (range 0–21, higher scores indicate greater anxiety or depression); MOS = Medical Outcomes Study Social Support Survey (range 0–100, higher scores indicate more social support)

Table 4

Mean Distress and Quality of Life Scores by Extent of Communication

Measure	Minimal communication (N = 7)	Partial communication (N = 13)	Full communication (N = 22)	p value, unadjusted	p value, adjusted*
HADS Anxiety	4.1	7.6	10.4	0.0007	0.003
HADS Depression	2.4	5.6	7.6	0.02	0.08

* Adjusted for ECOG score

Abbreviations: HADS = Hospital Anxiety and Depression Scale (range 0–21, higher scores indicate greater anxiety or depression); ECOG = Eastern Cooperative Oncology Group Performance Status Scale (range 0–4, higher scores indicate worse performance status)

Table 5

Major themes related illness-related communication and parental anxiety

Theme	Representative quotes	Participant characteristics
Participant acknowledgment of life-limiting prognosis	“They’re looking for a simple explanation for a horrible question. It’s hard to explain the cancer as one of those wicked things that can just anybody at any time. That’s the hard thing. Something so horrible and evil can be so evil and complicated and simple.”	44 yo mother with 1 dependent child, ECOG functional status = 3
	“I think they know that it’s a pretty bad cancer and they can tell that it’s took quite a toll on me.”	45 yo father with 2 dependent children, ECOG functional status = 3
Parental physical changes as motivation to communicate	“It’s one of those things where you don’t want to totally forget it’s there, because things, adjustments have to be made and I don’t have as much energy or stuff like that, so they need to be able to understand that, and we don’t like to keep the kids in the dark, so while they don’t get bombarded with details, they do know what’s happening.”	42 yo mother with 3 dependent children, ECOG functional status = 1
	“If I know I have to take chemo at home, I sit the kids down and I talk to them about it. That way they’re not like, “he’s got some huge bag with a motor hanging out of his chest, and it’s making all these noises, what is that Mom?”	45 yo father with 2 dependent children, ECOG functional status = 3
Parent-child communication as a source of anxiety	“that’s my biggest scare ... that I don’t know how to talk to them about it right now ... I don’t know how to get through her childishness.”	55 yo mother with 1 dependent child, ECOG functional status = 3
	“Just my youngest needs someone to help him understand, and he needs someone that really knows at his particular age, what he should be told and what he shouldn’t be told, and I just don’t think he understands.”	49 yo mother with 1 dependent child, ECOG functional status = 2
	“You don’t know what to expect so you don’t know how much to rattle them either so that’s sort a constant thing you think about is how much to reveal and when.”	50 yo father with 3 dependent children, ECOG functional status = 0