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An Exploratory Study of End-of-life Prognostic Communication Needs as Reported by Widowed Fathers due to Cancer

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Abstract

Objective—Effective physician communication about prognosis is a critical aspect of quality care for families affected by terminal illness. This is particularly important for spousal caregivers of terminally ill parents of dependent children, who may have unique needs for communication about anticipated death. The objective of this study was to explore end-of-life prognostic communication experiences reported by bereaved fathers whose wives died from cancer.

Methods—From October 2012 to November 2013 we surveyed widowed fathers whose wives died from cancer through an open-access educational website. The survey included the following open-ended questions regarding prognostic communication: “What is the most important thing you would like us to know about whether/how your wife’s doctors communicated with you about her anticipated death? What do you wish had been different, if anything?” We performed traditional content analysis of responses. Two researchers coded and categorized the data.

Results—Two hundred forty-four men responded to the survey questions on prognostic communication. Major themes addressed by respondents were the importance of clear and honest communication and physician bedside manner. They also identified unmet information needs, including wanting to know prognosis sooner. Relevant sub-themes included death coming as a surprise, avoidance, and caregiver regret.

Conclusions—Surviving spouses due to cancer can provide important insights for health care providers about optimum prognostic communication at the end of life. Increased physician attention to the communication preferences of both patients and their partners may improve bereavement outcomes for family members.

Keywords

Prognosis; Communication; Widows; Cancer; Oncology

BACKGROUND

Effective physician communication about prognosis is an essential aspect of quality care for patients with terminal illnesses and the family members caring for them [1, 2]. Prognostic discussions allow patients the opportunity to share their preferences about end-of-life care. They also help caregivers to facilitate psychosocial support for both the patient and themselves, foster shared decision-making about current and future care, and prepare for death and bereavement [3]. For patients with cancer, high quality communication about prognosis has been associated with greater satisfaction with medical care, less aggressive end-of-life care [4], and earlier hospice enrollment [3]. Although limited, previous research on family caregivers suggests that those who are unprepared for their loved one's death are at greater risk of psychological distress during the bereavement period [5]. For both parents with terminal cancer and their caregiver partners, accurate prognostic understanding also allows them to anticipate and prepare for the challenges the bereaved parent will face as a sole parent [6].

Discussions about anticipated death are nuanced, often iterative conversations that require skill and attention to the emotional and informational needs of both the patient and their caregivers [7]. Despite the emergence of literature on patient-physician communication, there is substantially less information on the prognostic communication needs of caregivers despite their integral roles for patients at the end of life. Data also suggest a need for improvement in communicating prognosis with family caregivers. In a large national study, one in four bereaved caregivers reported concerns about physician communication [8]. Other studies have demonstrated caregivers' desire for increased involvement in treatment and care decisions [9] as well as more specificity about their loved ones' illness process and prognosis [10].

Physicians rarely have the opportunity for extended contact with bereaved caregivers after their patients' deaths. Consequently, physicians do not typically receive important retrospective feedback about the family's prognostic and end-of-life communication needs. Despite the central role that spouses play in caring for patients with terminal cancer, few studies have specifically examined caregivers' experiences of prognostic communication at the end of their partner's life. The purpose of this investigation was to explore experiences of prognostic communication with physicians, as reported by bereaved widowers whose wives died from cancer and who have children in the home.

METHODS

Study design and sample

As part of an open-access educational website for widowed fathers due to cancer (www.singlefathersduetocancer.org), we conducted an online survey to assess these men's

experiences during and after the death of their children's mother (in nearly all cases, their spouse). This survey was available to all people who visited the website and self-identified as a father of one or more biological or adopted children whose mother died of cancer, when at least one of the children was under the age of 18. The survey included the following open-ended questions regarding prognostic communication between the respondent and his children's mother's physician: "What is the most important thing you would like us to know about whether/how your wife's doctors communicated with you about her anticipated death? What do you wish had been different, if anything?"

The website was advertised among colleagues at several large cancer institutions and through the media, including NBC's Today Show [11], the Associated Press [12], and the New York Times Health section [13]. Data from the online survey were collected between October 2012 and November 2013. Due to the small number of men who were not married to the mother of their children at the time of her death ($n = 9$), the analysis was restricted to married men. Informed consent was obtained prior to start of the survey, which was approved by the University of North Carolina (UNC) at Chapel Hill Institutional Review Board.

Data analysis

Electronic responses were uploaded into a qualitative analysis software program (NVivo 10, QSR international). Data were analyzed using constant comparative method of analysis [14, 15]. The goal of this analysis was to identify and characterize men's experiences of communication with their wife's physician about her advanced cancer prognosis. All responses were read line by line by two investigators (EP, DC) to begin the coding process. Coders independently assigned inductive descriptive codes to themes identified in the text, using the respondents' own language when possible. During joint meetings, thematic categories were created from groups of related codes and a final code structure was developed through this process. The final code structure was then independently re-applied to the texts by the investigators followed by joint sessions to discuss differences, which were resolved through negotiated consensus [16]. Frequency counts of identified themes were also employed in data analyses [17]. Cohen's Kappas ranged from .649 to 1, indicating moderate to high inter-rater reliability. Descriptive statistics were compiled to characterize the demographic characteristics of the sample, including frequency distributions, means, ranges, and standard deviations as appropriate.

RESULTS

Demographics

Two hundred and forty-four men, self-identified as fathers of dependent children at the time of their wives' deaths, completed the open-ended survey questions about prognostic communication. Demographic characteristics of the sample are listed in Table 1. Respondent age at time of survey was an average of 44.3 years ($SD = 7.5$). The mean age of their wives at time of death was 44.1 years ($SD = 7.2$). Nearly half (47.3%) of the sample completed the survey within 1 year of her death and over a third of respondents completed the survey

within six months of her death. Sixty-eight percent of respondents reported that their wives had received hospice services.

Major themes

Nearly all men (82%) who completed the general questionnaire offered at least one comment about how their wife's prognosis was communicated by her physician, with many men writing extended descriptions of their experiences. Seventeen percent of respondents stated that nothing could have been different with regard to prognostic communication. Men who identified areas of need described the delivery, content, or timing of the discussion. We identified four major themes: (1) the need for honest and clear communication from physicians; (2) the need for earlier prognostic information; (3) the need for more specific information about the end of life; and (4) the importance of bedside manner. We also identified three sub-themes: (1) death as a surprise; (2) avoidance of prognostic communication; and (3) caregiver regret. Interestingly, children and the parental roles of men and their wives were rarely mentioned. Direct quotations from participants are in italics. Important themes are summarized in Table 2.

Honest and Clear Communication—The need for honesty and clarity of communication by physicians were the most frequently described characteristics of prognostic communication reported by the surviving spouses in our sample. Twenty-eight percent of respondents discussed the importance of honesty on the part of their physicians and 24% described the need for physicians to communicate clearly about prognosis.

Many respondents believed that their wife's physician was purposely transparent. More rarely, respondents felt the provider was intentionally withholding information. For example, 11% of respondents specifically reported feeling misled by information that was presented as overly optimistic. More commonly, men described a pattern of avoiding discussions of prognosis that was only realized after their wife's death and this sub-theme of avoidance was commonly identified in the respondents who reported the need for honest communication. Often, men believed that the physician, their wife, or they themselves had avoided these conversations in order to preserve hope. Several respondents recognized the difficulty in balancing clear and honest communication with the need for hope, many acknowledging their own ambivalence about which they preferred.

“Her doctors always tried to stay positive but never truly came out and said she was going to die. They repeatedly told us they'd know when we got to that point. That talk never really came. We stayed upbeat and positive until the end. In retrospect, I'm still unsure if knowing for sure or holding strong hope would be better.”

Other respondents who did have explicit conversations with their wife's physician described honest communication as “blunt,” and “painful.” These conversations were largely appreciated, though not necessarily at first. Very few respondents in this sample voiced regret that physicians were honest or clear about their wife's prognosis. Instead, they specifically noted the benefit of honest communication because it allowed them to prepare for end of life.

“We had a blunt conversation from the start. It was tough, but ultimately made us informed and allowed us to be better prepared for everything to come.”

Honest and clear communication that facilitated end-of-life preparation was particularly important because of the proportion of respondents (12%) who described feeling surprised or shocked by their wife's death. Those who described their wife's death as happening suddenly were more likely to also describe unclear or misleading communication with physicians.

Wish for earlier prognostic communication—Although it appears that most men in our sample understood their wives had incurable conditions, death often occurred sooner than expected. Several men specifically noted that neither they nor their children had the opportunity to say good-bye to their wives due to misunderstanding about how much time they had left with them. Many men shared a belief that important conversations were deferred because of inaccurate understanding of prognosis.

“Maybe we could have changed our discussions from the fight and the forward thinking of what we'll do next, to what needed to be said to each other right then, right when our last few conversations meant the most.”

Several men commented that their understanding of how much time their wives had left to live impacted treatment decision-making near end of life. They described a wish for earlier and more accurate understanding of their wife's prognosis and regretted not utilizing hospice or palliative services sooner. Others noted they would have deferred additional chemotherapy, with several men reporting that their wife received treatment within days to weeks of her death. This subtheme of regret that they had not better utilized their time with their wives was commonly represented among the respondents who desired earlier prognostic communication.

The desire to understand the “timeframe” at the end of their wives' lives was a source of impassioned responses for many of the men, with some specifically stating that they relied upon their wife's physician for this information. Many did not realize how rapidly death could occur and did not have important conversations with their wife as a result.

“As she began to weaken the weeks before her death, it would have been nice if the doctors would have taken me aside and said this is not looking good, so I could prepare my boys, instead they waited until she was in a coma to tell us that there was nothing they could do.”

Additional information about end of life—Thirty-three percent of respondents believed they needed more information about what to expect about their wives' disease courses, death processes, potential treatment complications, and palliative and hospice care. They described the journey of their wives' advanced cancer as overwhelming, uncharted territory.

“...maybe it was our naiveté but we sometimes felt like we were kindergartners tossed into high school, and everyone expected us to know what was going to

happen...we didn't know, and trying to figure what questions to ask was really tough, and not to mention a little disheartening.”

Death as a surprise was an important subtheme to both the need for more information about end of life and wish for honest and clear communication. Among the respondents who were surprised about the suddenness of their wives’ deaths, many lost their wives due to treatment or disease-related complications such as infection. These men expressed a desire for earlier and more specific conversations that would have described the spectrum of possible illnesses and the unpredictable nature of her disease course that could affect their wives in their compromised states.

“We pursued treatment until the end.... I was expecting one more scan result that would prove to both of us that we have tried everything medically possible, thus providing the freedom to pull back from curative treatment. However an infection in her one good lung proved fatal before we got there. I wish we knew that those types of scenarios were a much more realistic possibility at our stage in the fight. But at the same time, looking back, I guess I should have known.”

Although our sample included a large number of men whose wives utilized hospice services, several noted they were unable to fully utilize available hospice programs due to the limited time their wife spent in hospice care or misunderstanding about what hospice could offer.

Bedside Manner—The manner in which physicians discussed prognosis was critically important to men in this sample. Physician delivery of information, such as vocal tone, body language, and allowing time for the couple to grieve and process during their discussions, greatly impacted how this information was perceived. Twenty-six percent of men discussed positive or negative examples of physician bedside manner or the way in which their wives’ physicians delivered prognostic information. Specifically, 12% cited the importance of physician compassion when delivering bad news.

“They never sugarcoated details but at the same time were very caring and sympathetic to my feelings/emotions.”

CONCLUSIONS

Timely, compassionate and direct communication about prognosis allows patients with advanced illnesses and their loved ones to prepare for death. Our study is the first to ask bereaved fathers whose wives died from cancer to describe their experiences of physician communication about prognosis. While prognostic discussions about advanced cancer and expected death are complex and highly individualized, our data suggest several potential areas for improvement in prognostic communication between physicians, patients, and their partners.

The surviving spouses in our sample wanted information that was honest, clear, specific, and delivered in a compassionate way. While many men in our sample expressed a wish for more precise information about expected death, this was not universal, and some families appreciated avoidance in the service of hope. More importantly, respondents in our study wanted information about all aspects of anticipated outcomes of their loved one's illness.

This was not limited to life expectancy but also included symptom management, treatment complications, changes in functional status, and how to best care for their wives. A broader definition of prognosis reflects this inclusive approach [18] although it is unclear how often this occurs in practice.

The desire for more prognostic information may also reflect the younger age of the men our sample. Several studies have demonstrated that younger age – for both patient and caregiver – is associated with an increased desire to know more information about illness and prognosis [19, 20]. Previous research also suggests that patients and their caregivers have differential informational needs about prognosis at the end of life, with caregivers seeking more information and patients seeking less [18, 21]. Given the number of respondents who reported feeling surprised by their wife's death, it may be that satisfactory prognostic information for patients is inadequate for their caregivers. This may have important implications for the caregiver's sense of regret or surprise about their loved one's death as well as risk of worse mental health and bereavement outcomes. Data from a population of bereaved men who have lost their partners due to cancer indicate that lack of preparedness is associated with long-term adverse psychological symptoms [22]. Previous data also suggest that lack of preparedness for partner's death increases the risk for complicated grief [5]. These syndromes of complicated grief and mood disorders can themselves place bereaved caregivers at higher risk of adverse health problems [23, 24].

Surprisingly, parental concerns were infrequently mentioned by respondents. While they noted their wife's role as a mother, most men focused more on their own loss when answering these survey questions. We suspect the importance of prognostic communication may be especially important for dying parents with dependent-age children at home. However, our data neither refute nor support this hypothesis. When children were mentioned, it was typically in the context of them saying goodbye to their mothers. A cross-sectional national survey of patients, providers, and family members about “good death” revealed that family preparation and saying goodbye to important people are commonly held values. This study demonstrated that these values are particularly important for patients' spouses as well [25].

There are several limitations to our study. Our assessment of prognostic communication needs was cross-sectional and retrospective. Longitudinal studies that assess caregiver communication needs both before and after death would advance this line of research. It is both a strength and limitation that our analysis was generalized to caregivers' prognostic communication needs. While this allowed us to identify themes applicable to all family caregivers, follow-up open-ended questions that assessed how the parental role and presence of children impacted their prognostic communication needs would have been ideal and will be incorporated in future assessments. In addition, due to the open-access nature of our website and survey, we could not confirm whether respondents met eligibility criteria. However, given the emotionally sensitive nature of our survey, it is unlikely that respondents would falsely identify themselves as bereaved fathers due to cancer. A related limitation concerns the representativeness of our sample. Respondents were a group of men with above average levels of education and income and were primary Caucasian. Additionally, 68% of respondents' wives used hospice services which is higher than the national average of 44.6%

[28]. Further, it is possible that bereaved fathers who sought our website and took the survey were more likely to be distressed about their wife's death than typical bereaved spouses.

Despite these limitations, this study benefits from numerous in-depth reflections about prognostic communication from the perspectives of bereaved spouses. While we sought to characterize the experiences of a unique population, these fathers' experiences of prognostic communication are relevant to a broader range of families affected by cancer or other illnesses. Indeed, very few of their comments were specific to their role as fathers, and therefore, their answers can inform prognostic communication for other bereaved caregivers. By focusing on only men, we have more clearly elucidated the prognostic communication and bereavement needs of a group that is less likely to receive social support during the bereavement period [29].

There is a need for additional research on how to optimize communication and support for caregivers both before death and during bereavement. Structured communication skills training with health care providers should incorporate the needs of not just the patient but also their caregivers and how to balance both of their needs during the same visit. Another group of investigators, Clayton et. al, have suggested separate meetings with the patient and caregiver given their differential information requirements at the end of life [21]. At UNC - Chapel Hill, we hold a unique support group for widowed fathers due to cancer. Peer support in groups such as ours may help bereaved caregivers address unresolved distress regarding prognostic communication and the often unexpected nature of death.

In summary, addressing emotional and informational needs of family members is a critical aspect of high quality end-of-life care [8]. Increased physician attention to the prognostic communication preferences of both patients and their family caregivers may improve outcomes for bereaved family members.

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Table 1

Respondent characteristics

Characteristic	Respondents (<i>n</i> = 244)	Percent (%)
Mean age (SD)	44.3	7.0
Race/ethnicity		
Caucasian	215	91.5
Non-Caucasian	20	8.6
Education		
High school graduate, GED or some college	59	24.8
College degree	81	34.0
Post-graduate degree	98	41.2
Annual household income		
< \$50,000	55	23.5
\$50,000 – \$100,000	71	30.3
> \$100,000	108	46.2
Number of minor children at time of wife's death		
1	77	31.6
2	118	48.4
3	35	14.3
4 or more	14	5.7
Time since wife's death, months		
0-6	83	34.4
6-12	31	12.9
12-24	44	18.3
> 24	83	34.4
Wife received hospice services		
Yes	166	68.0
No	73	29.9
Unsure	5	2.0

Table 2

Major themes

Theme	Representative quotes
Honesty and clarity	<p><i>"My wife's doctor was very candid and straightforward throughout her treatment. My wife's doctor(s) gave us direct answers to all of your questions. I do not believe anything related to our communication with her doctor could have been improved."</i></p> <p><i>"When it finally happened it was a bit of a shock. I wish they were clearer with me."</i></p>
Wish for earlier prognostic communication	<p><i>"Sooner – finding that balance between hope/optimism and realism, by the time it spread to her brain it was too late – should have discussed probably outcomes so we had more time to prepare while she was still high functioning."</i></p> <p><i>"Would have been nice to know the timeframe sooner. Towards the end everything happened so fast we never got to say goodbye to each other."</i></p>
Needing more information	<p><i>"They were very open and honest about her prognosis, but really didn't prepare us for how things would progress and what to expect as the disease progressed."</i></p> <p><i>"Without question, the single most difficult thing for me was that I had all the resources lined up that I could possibly think of – medication, home care, hospice, etc., and there was not one single thing that was offered to me as the caregiver as to what I could use as support for me and my children."</i></p>
Bedside manner	<p><i>"All doctors should have some formal training in psychology around grief and loss and delivering news with empathy and sympathy."</i></p> <p><i>"His candor, wisdom and comfort in helping me understand the peaceful nature of her inevitable passing was an incredible gift."</i></p>
Death as a surprise	<p><i>"We never talked about death. It was a complete surprise when it happened because we were too focused on the hope of survival."</i></p> <p><i>"We were never given any indication that my wife was going to die...Only after her death, when I questioned him did he acknowledge that his prognosis of a cure had changed and he was just hoping to put her into remission."</i></p>
Avoidance	<p><i>"I always felt he was avoiding the conversation. Reflecting back, I believe he wanted us to continue our optimistic outlook that had served us so well over the previous ten years. I just wish the doctors would have just said there was no bouncing back from this one."</i></p> <p><i>"We never asked how long she had because we didn't want that to effect her fight. So they did what we wanted."</i></p>
Caregiver Regret	<p><i>"I wish someone had shook me and told me what I need to do. I was in a lot of denial."</i></p> <p><i>"I wish I understood how fast the end comes so I could have taken her to Hospice."</i></p>