



Short communication

End-of-life parental communication priorities among bereaved fathers due to cancer



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ABSTRACT

Objectives: To elicit widowed fathers' perspectives on which domains of parenting-related communication they consider most important for dying parents to discuss at the end of life (EOL).

Methods: Two hundred seventy nine fathers widowed by cancer completed a survey about their own depression and bereavement symptoms, their wife's illness, and EOL parental communication priorities. Chi square and Fisher's exact tests and logistic regression were used to evaluate relationships between maternal EOL characteristics and fathers' responses to parenting-related EOL communication priorities. **Results:** Fathers identified raising children in a manner that reflected maternal wishes, whether/how to talk with children about their mother's death, and how the mother wanted to be remembered as the most important EOL communication domains. Fathers who reported that their dying wives were worried about the children were more likely to prioritize raising children in ways that reflect her wishes ($p = 0.01$). Other EOL characteristics were not associated with communication domains.

Conclusions: Communicating with children and maintaining emotional connection with the deceased parent are important priorities for bereaved fathers who lost a spouse to cancer.

Practice implications: Health care providers working with seriously ill parents may improve family outcomes by supporting communication at the EOL between co-parents.

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1. Introduction

Remarkably little research has examined communication between patients with advanced cancer and their family members. The end-of-life (EOL) communication literature focuses on prognostic disclosure [1–3], advance care planning [4,5], or the interactions between patients and their health care providers [6–8]. Yet, what is shared between dying patients and their family members is directly relevant to patients' psychological well-being [9] and surviving family members' bereavement outcomes [10–12]. This is particularly relevant for patients with advanced cancer who have dependent children and their co-parents, both of whom

experience extraordinarily high psychological distress at the EOL [13,14].

In the United States, cancer is the leading cause of death among women 35–54 years old [15]. Unlike parental death due to acute trauma, parents with chronic but incurable illnesses have the opportunity to prepare their families for their death and address important parenting concerns with family members.

Due to the practical and potential ethical difficulties of studying patients who are actively dying, EOL research frequently utilizes the perspectives of bereaved caregivers to understand the experiences of patients [16–18]. Findings from our previous studies on bereaved fathers suggest there is inadequate communication between terminally ill mothers and their families [19,20]. A majority of widowed fathers with dependent children reported that their wife did not say good-bye to their children prior to death [20]. Given the importance of parenting roles and parenting responsibilities for dying parents, it is imperative to understand parents' communication priorities at the EOL. Yet there are no

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published reports on what conversations dying parents or their caregivers believe are most important.

The aim of this exploratory study was to query bereaved fathers about parenting-related communication priorities when a mother of dependent children is dying. We also examined whether these opinions differed over time or in relation to her EOL experiences.

2. Methods

2.1. Study design and sample

We conducted a survey of self-identified widowed fathers through an open-access educational website (www.singlefathers-duetocancer.org). Descriptions of study participants and details about the development and distribution of the survey were previously reported [20,21]. Data were collected between October 2012 and December 2014. The current analysis focuses on the 279 men who were married to their children's mother, had a child under the age of 18 years at the time of her death, and responded to the survey within 27 months of her death. Informed consent was obtained prior to start of the survey, which was approved by the University of North Carolina-Chapel Hill Institutional Review Board.

2.2. Survey

Fathers completed the Center for Epidemiologic Studies Depression Scale; CES-D [22] and Texas Revised Inventory of Grief; TRIG [23]. Other validated measures included in the larger study of these men are described elsewhere [20,21]. The survey included multiple questions about the mother's cancer history and EOL experiences, such as location of death, presence or absence of hospice care, and prognostic awareness. Using investigator-designed questions, fathers reported on their wife's psychological and parenting concerns at the EOL (Table 1). These 4-point ordinal response scale questions (0 = "not true at all" to 3 = "very true") were collapsed into two categories for analyses: very/mostly true and little/not at all true. Fathers were asked to identify domains of parenting-related EOL communication they considered important with the question: "Knowing what you do now, what would you say are the most important topics a father should discuss with his children's mother when it becomes clear that her life will soon end? Please select up to three." All data were collected online using Qualtrics software (Qualtrics, LLC, Provo, UT).

2.3. Data analysis

We used descriptive statistics to characterize the sample of widowed fathers and their wives. For each parenting communication priority, responses were grouped based on whether or not fathers ranked that item in their top three. All EOL, demographic, and psychological score variables were compared between these groups using Fisher's Exact test or two group *t*-test. Given the

exploratory nature of this study, no modeling was performed and only results significant at the 0.01 level were considered statistically significant. Analyses were performed using SAS version 9.3 (SAS Institute, Inc., Cary, NC).

3. Results

See Table 2 for respondents' socio-demographic characteristics and Table 3 for mothers' demographic, illness, and EOL characteristics. Fathers identified the following four domains as the most important topics to discuss with a dying parent before death: how the mother would like the children raised, how the mother wants to be remembered, speaking with the children about the mother's impending death, and speaking with the children about their mother's death after she passes (Fig. 1). Fathers' responses to these communication priorities did not significantly differ with time since death, TRIG scores, or CES-D scores. Fathers who identified dating or remarrying as a communication priority were more likely to report lower TRIG scores (40.8 vs. 47.3, $p < 0.001$).

Most fathers' demographic characteristics were not associated with communication priorities. The respondents who identified as non-Caucasian ($n = 35$) were more likely to prioritize discussing day-to-day household management (37% vs. 15%, $p = 0.004$). Caucasians were more likely to select funeral/burial wishes (31% vs. 9%, $p = 0.004$). Fathers who reported that religion was not important were more likely to prioritize talking with children about their mother's impending death (54% vs. 32%, $p < 0.001$) and fathers who reported higher income were more likely to select how their wife wanted to be remembered (53% vs. 35%, $p = 0.005$). Father's age, employment status, education level, number of children, and children's age were not significantly associated with selection of any communication priorities. Caucasian respondents were more likely to report being sole caregivers (91% vs 71%). Otherwise, there were no differences between respondents by race.

Duration of the mother's metastatic illness, participation in hospice care, saying goodbye to family members, and level of prognostic clarity were not associated with any of the communication domains. Most fathers reported that their wives were worried about the strain on them (80%) as well as the children (90%) at the EOL. Those who believed she was worried about the children were more likely to select raising children in ways that reflect her wishes as a priority for communication (60% vs. 35%, $p = 0.01$).

4. Discussion and conclusion

4.1. Discussion

Our results highlight several key points relevant to the care of dying mothers and their families. First, communication priorities were remarkably consistent among respondents and over time, suggesting that the essential domains of parenting-related

Table 1
Complete response options for questions about maternal end-of-life experiences.

Question 1	How clear do you feel [your wife's] doctors were with her about her prognosis?
Question 2	Now thinking about the final weeks of [your wife's] life, how true would you say each of the following statements is?
	She was at peace with dying.
Question 3	She was worried about the strain on the children
Question 4	She was worried about the strain on you
Question 5	She and the children had said 'goodbye' to each other
Question 6	You and she had said 'goodbye' to each other

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