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

Eliza M Park^a, Allison M Deal^b, Justin M Yopp^a, Teresa Edwards^c, Elise M Stephenson^d, Claire E Hailey^d, Zev M Nakamura^a, and Donald L Rosenstein^{a,e}

^aDepartment of Psychiatry, University of North Carolina, Chapel Hill, NC (USA); 170 Manning Drive, Chapel Hill, NC 27599, USA

^bLineberger Comprehensive Cancer Center Biostatistics Core Facility, University of North Carolina, 450 West Drive, Chapel Hill, NC 27514, USA

^cH. W. Odum Institute for Research in Social Science, University of North Carolina at Chapel Hill, 208 N. Raleigh St, CB3355, Chapel Hill, NC 27599, USA

^dSchool of Medicine, University of North Carolina, 321 S. Columbia St., Chapel Hill, NC 27516, USA

^eDepartment of Medicine, University of North Carolina, 125 MacNider Hall, CB7005, Chapel Hill NC 27599, USA

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

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Corresponding author at: Eliza M Park, MD, Department of Psychiatry, University of North Carolina, 170 Manning Drive, Campus Box #7305, Chapel Hill, NC 27599 USA, Phone: 919-966-3494, Fax: 919-966-6735, leeza_park@med.unc.edu.

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Conflict of interest

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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.

Keywords

Communication; bereavement; parents; cancer; oncology; end-of-life

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 to 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 goodbye 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 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.singlefathersduetocancer.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 (Figure 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 communication are common across families and less dependent on the demographic or illness characteristics of the parents.

Second, our study supports the importance of parental communication with children about death. Parents with terminal cancer identify illness-related communication with children as a source of concern and many report that they lack the necessary confidence or information to effectively communicate with their children.[24, 25] These data reinforce the need for additional resources to assist dying parents and their co-parents with this challenging task.

Third, fathers noted the importance of receiving guidance from the children's mother about healthy ways to keep their children emotionally connected to their mother after her death. Existing research suggests that children who maintain continued bonds with their deceased parent experience better emotional health and adaptation.[26] Data from this study underscore the potential value for surviving fathers in discussing such issues prior to their partner/spouses' death. For parents with terminal illnesses, discussions about how to facilitate their children's coping during bereavement can be extraordinarily difficult due to the intense emotional distress this may engender. Not surprisingly, conversations between

co-parents often do not occur despite their potential benefit. Although inadequately studied, interventions to enhance communication between ill and healthy parents may lead to improved mental health outcomes for the entire family unit.

The present findings should be regarded as preliminary because of study limitations. Reported here are the perspectives of bereaved fathers on prioritized parental communication needs. The communication priorities of dying fathers or unmarried co-parents may differ and these questions are worthy of future exploration. The limited representativeness of our sample reflects the need for additional study of this topic with a more diverse group of bereaved parents, which might yield additional priority areas of communication. Additionally, we were unable to analyze what was actually communicated between parents; these data only capture one parent's opinion about the importance of a given conversation topic.

4.2. Conclusion

There are multiple benefits to clear, candid communication about parenting priorities for parents with advanced cancer and their loved ones. Such conversations can help meet the dying parent's goals of care,[19] identify areas of parenting concern, help the surviving parent with parenting,[27] and facilitate children's adjustment.[27, 28] Pre-death conversations that anticipate future challenges may reduce the surviving parent's psychological distress in bereavement. This is an almost entirely neglected area of research in the EOL literature despite the elevated levels of depression and anxiety in widowed parents.[13, 14] Although challenging, studying family communication needs at the EOL is critically important to improving patient and family outcomes.

4.3 Practice Implications

Our study supports the role of health care providers in encouraging and providing guidance regarding illness-related conversations between parents of dependent children and their families at the EOL.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Highlights

- Web-based survey of bereaved fathers due to cancer.
- Communication with children about death is a priority for bereaved fathers.
- Fathers identify maternal wishes about raising children as important to discuss.
- Communication priorities of fathers do not differ with time since death.

Figure 1.

*Respondents were asked to choose top three priorities, so percentages will not add up to 100.

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

Table 2

Respondent characteristics

Characteristic	Total sample (N = 279)	
	n	%
Age, years, mean (SD)	260	45.9 (7.4)
Number of children aged < 18 years, mean (SD)	279	2.0 (0.9)
Age of youngest child at time of mother's death, years, mean (SD)	277	8.1 (4.9)
Time since mother's death to survey, months, mean (SD)	278	8.6 (7.7)
Caucasian race	223	86.4
College graduate	189	72.7
Employed	220	85.2
Annual household income, \$		
Less than 50,000	62	24.0
50,000 – 100,000	89	34.5
More than 100,000	107	41.5
Current sole caregiver	232	88.9
Religious faith important	178	68.2

Table 3

Mother demographic, illness, and EOL characteristics

Characteristic	Total sample (N = 279)	
	n	%
Age, years, mean (SD)	277	40.7 (7.4)
Time between diagnosis and death, years, mean (SD)	277	3.1 (3.3)
Cancer site		
Breast	99	35.6
Gastro-intestinal	19	6.8
Gynecologic	27	9.7
Lung	19	6.8
Brain	15	5.4
All other	99	35.6
Metastatic disease at diagnosis	116	46.8
Hospice services received	190	68.1
Location of death		
Home	116	41.6
Hospital	109	39.1
Hospice facility	53	19.0
Other	1	0.4
Death at location of choice		
Yes	128	45.9
No	51	18.3
Unsure	8	2.9
Had not expressed a preference	92	33.0
Mother had prognostic clarity (Q1) *	205	73.5
Mother was at peace with dying (Q2) **	131	47.6
Mother was worried about children (Q3) **	250	89.6
Mother was worried about spouse (Q4) **	223	80.2
Mother said goodbye to children (Q5) **	109	39.2
Mother said goodbye to spouse (Q6) **	145	52.2

Abbreviations: EOL = End of life; Q1–6 = Question 1–6 of Table 1.

* “Completely” or “Mostly clear on a four-point scale, as reported by the father.

** “Very” or “Mostly” true on a four-point scale, as reported by the father.