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## Family Caregivers' Perspectives on Communication with Cancer Care Providers

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### Abstract

**Purpose/Objectives:** Family caregivers of individuals living with cancer are often highly involved in communication with healthcare teams, yet little is known about their experiences, needs, and preferences in this role. To address this gap in the knowledge base, researchers sought to explore family caregivers' perspectives on communication with oncology care providers.

**Design and Methods:** Researchers conducted a secondary inductive thematic analysis of qualitative interviews originally collected as part of a randomized clinical trial of a supportive intervention for family caregivers of patients with cancer ( $N = 63$ ).

**Participants:** Participants were family caregivers of adult patients with cancer. Most were patients' spouses/long-term partners (52.3%) or adult children/grandchildren (29.2%). Caregivers of patients with all cancer types and stages of disease progression were eligible for study enrollment.

**Findings:** Caregivers valued communication with healthcare providers who were attentive, genuine, broadly focused on patients and caregivers' experiences, sensitive to unmet information needs, and responsive to the potentially different communication preferences of patients and caregivers.

**Interpretation:** Family caregivers expressed a strong preference for person-centered communication, conceptualized as communication that helps healthcare providers meet the needs of patients and caregivers both as individuals and as an interdependent unit of care, and that acknowledges individuals' experiences beyond their prescribed roles of "cancer patient" and "caregiver."

**Implications for Psychosocial Oncology Practice:** Psychosocial oncology providers' strong orientation to the biopsychosocial and spiritual aspects of cancer care delivery make them uniquely positioned to support family caregivers. Findings suggest that providers should explicitly

communicate their commitment to both patient and family care, involve family caregivers in psychosocial assessment activities and subsequent intervention, and strive to honor patients and caregivers' potentially different communication preferences.

### Keywords

caregiver; communication; family; oncology; cancer; qualitative research

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### Introduction

Clinicians and researchers alike have long asserted that effective care for patients with cancer and other life-threatening illnesses is “inextricably bound with and dependent upon effective communication.”<sup>1</sup> It is perhaps unsurprising, then, that the topic has been extensively researched, resulting in a robust body of evidence to inform dyadic provider-patient interactions.<sup>2,3</sup> Research has shown, for example, that patients tend to prefer provider communication that is responsive to both the informational and emotional components of their concerns,<sup>4</sup> that acknowledges their decision-making capacity,<sup>5</sup> and that is appropriate to the stage of their disease progression.<sup>6</sup> With regard to outcomes, studies have shown that effective provider-patient communication enhances pain and symptom management,<sup>7</sup> ameliorates patients' psychological distress,<sup>8,9</sup> and improves patients' satisfaction with care.<sup>10</sup>

There is growing recognition, however, that communication in cancer care delivery is often triadic rather than dyadic, involving not just the provider and the patient, but also a family member or friend in a caregiving role.<sup>11,12</sup> Compared to research on patients' views, much less is known about cancer family caregivers' perspectives on provider communication. One study, which focused on advanced cancer care, highlighted the challenges inherent in discussions about end-of-life issues. While many caregivers in the study reported a lack of accurate information regarding the patient's prognosis and treatment options, many also expressed an ambivalence about their preferences related to communication about “bad news.”<sup>13</sup> Waldrop and colleagues<sup>14</sup> also studied provider-caregiver communication in the context of advanced cancer care. In their study, family caregivers described unsatisfactory communication as sparse, conflicted, contradictory, and “brink-of-death” (i.e., blunt communication when death was imminent). In another study, the two most commonly endorsed information needs among caregivers of patients with head and neck cancer related to communication. Specifically, they expressed a desire for more information about “knowing what questions to ask” healthcare providers and knowing “how to talk with doctors or nurses.”<sup>15</sup>

The existing evidence on provider-caregiver communication, while presently limited in size and scope, nonetheless reveals numerous opportunities to better support the individuals most closely involved in patients' day-to-day care.<sup>11</sup> In the analysis described herein, researchers closely examined family caregivers' first-hand accounts of communication with oncology care providers, seeking to better understand caregivers' perspectives on provider communication and its role in cancer care delivery. The following question guided the

analysis: *How do family caregivers of patients with cancer describe effective provider-caregiver communication?*

## Methods

Researchers conducted a secondary analysis of individual interviews of participants ( $N = 63$ ) of a small randomized clinical trial (RCT) of a technologically-mediated problem-solving intervention for family caregivers of cancer patients receiving outpatient palliative care services from an academic health system in the Midwestern United States. Family caregivers participating in the trial were randomly assigned to receive either usual care (Group 1) or usual care plus a three-session problem-solving intervention (Group 2). Regardless of the group to which they were assigned, all participants took part in an interview upon exiting the study. The goal of the interview was twofold: 1) to learn more about the caregiving challenges faced by study participants, and 2) to provide caregivers who received the intervention an opportunity to provide feedback on its content and delivery. All research activities were approved by the University of Missouri Institutional Review Board (Project #2002215) and registered at [clinicaltrials.gov](https://clinicaltrials.gov) (NCT02427490). Inclusion criteria for the RCT required that each participant was the adult family caregiver of an adult patient with a cancer diagnosis who was receiving palliative care either concurrent with disease-directed treatment or as a stand-alone service. Study participation was open to all individuals involved in the patient's care who were defined as a "family caregiver" by the patient; no biological or legal relationship was required. Additionally, caregivers of patients with all cancer types and stages were eligible for study enrollment. Detailed information on the full RCT has been previously published elsewhere.<sup>16</sup> A summary of participant characteristics is provided in Table 1.

All interviews were conducted by a trained member of the research staff (a registered nurse or masters-prepared social worker). Caregivers who exited the trial early (most commonly due to patient death) were allowed to choose whether to participate in an interview. Approximately 22% of the clinical trial participants (18 of 83) declined to be interviewed, and audio-recording failed during 2 interviews, resulting in a final analytic sample size of 63. Interviews were conducted in person or via telephone, depending on participant preference, and lasted an average of 29.6 minutes ( $SD = 14.5$  minutes).

As is common in qualitative research,<sup>17</sup> the interview guide evolved over time. An early version inquired generally about challenges participants had faced in their caregiving role. When preliminary analyses revealed a striking number of problems related to communication with healthcare providers, researchers modified the interview guide to include specific questions about provider communication. Approximately half ( $n = 32$ ) of the study participants were interviewed using the original interview guide, while the remainder were interviewed with the final modified version ( $n = 31$ ). Questions included in both versions of the interview guide are provided in Table 2.

## Data Analysis

All digitally recorded interviews were transcribed verbatim by a contracted third-party service and verified by a member of the research team prior to being subjected to inductive

thematic analysis, as outlined by Braun and Clarke.<sup>18</sup> Three medical students conducted the analysis under the supervision of two faculty investigators (a social worker/qualitative researcher and a palliative care physician). After reading the interview transcripts to familiarize themselves with the data, the medical students manually applied descriptive labels to communication-related data extracts in the same six interviews (approximately 10% of the dataset) and then met together with their faculty supervisors to develop an initial codebook. Next, they divided the remaining interviews, ensuring that each transcript would be dually coded. All revisions to the study codebook or changes to individual coding decisions were made by a consensus of the analysts and were reviewed by at least one of the faculty supervisors. When all coding was completed, the research team met to consider a list of candidate themes, eventually defining and describing finalized themes. Take, for example, the following data segment: “For us, [the problem] was just not really being aware of what we were about to get into at all with anything.” When coding, both analysts applied numerous codes to this passage such as “uncertainty” and [not] “knowing what to expect.” This coded segment was later combined with other similar segments, comprising the candidate theme “information need.” While the theme was ultimately retained as a final theme, its definition was refined, allowing the findings to reflect not just the importance of providing factual information, but also explaining how those facts would affect patients’ and caregivers’ everyday lives.

### Strategies to Enhance Rigor

Several strategies were employed to enhance methodological rigor. Family caregivers were well known to the faculty investigators, as the caregivers had taken part in the larger RCT from which data were drawn, permitting prolonged engagement at the study site (minimum of two years for all faculty investigators) and persistent observation of the family caregiver experience in palliative oncology care.<sup>19</sup> Medical students on the research team had both didactic and experiential training in palliative care and qualitative data analysis, overseen by the study physician and qualitative methodologist, respectively. Dual coding and both supervised and independent peer debriefing allowed medical students in the qualitative analyst role to question emerging understandings of the data and challenge one another’s potential biases with regard to the study findings. All coding decisions were agreed upon by a minimum of two members of the research team; coding discrepancies were resolved via thorough discussion and consideration of multiple points of view.<sup>19</sup> Finally, a detailed audit trail containing raw data, coded data, and methodological process notes was maintained and regularly reviewed by supervising faculty investigators during regularly scheduled research team meetings.<sup>19</sup>

### Results

Researchers identified five themes that summarized family caregivers’ perspectives on communication with healthcare providers. Specifically, they found that caregivers valued communication with healthcare providers who were (1) attentive, (2) genuine, (3) broadly focused on patients and caregivers’ experiences, (4) sensitive to unmet information needs, and (5) responsive to the potentially different communication preferences of patients and

caregivers. Each of these themes is described in detail below. Study numbers are used in lieu of personally identifiable information to ensure participant confidentiality.

### **Caregivers value communication with attentive providers.**

Caregivers repeatedly commented on the importance of healthcare providers' attentiveness. In many instances, they equated being attentive with "taking time" and "listening." For example, one caregiver (P007) described her interactions with the advanced practice nurse on the palliative care team: "She's a listener. You know what I mean? She actually takes the time to sit there and listen and poke and prod and figure out exactly what the problems are and then come up with something that helps that." In recalling their impressions of providers' communicative behavior, a number of participants distinguished between the attentiveness involved in "really" listening and other types of presumably less engaged listening. "I really like that, you know? Whenever you're really talking to somebody and you know for a fact that they're really listening to you," explained one caregiver (P022).

Several participants specifically mentioned the importance of providers paying attention to them as caregivers, contrasting this with the behavior of providers who focus solely on the patient. One participant (P018) stated that she liked working with providers who shared information with her in addition to the patient, helping her "feel involved ... instead of just sitting by." Another (P037) commented, "A lot of times the caregivers are overlooked, [but] they're the ones that are doing the backbone of [the care]." Describing positive interactions with her husband's providers, one patient's wife explained, "The funny thing about it is [they] not only ... ask [my husband], they ask me, 'How are you doing?' And most people don't take the time out to ask" (P012).

### **Caregivers value communication they perceive to be genuine.**

In addition to provider attentiveness, caregivers commonly cited provider genuineness as a necessary ingredient in effective communication, contrasting this with more distant or "professional" approaches. One caregiver (P016) discussed his dissatisfaction with his wife's final visit with her primary oncology team: "When you go through [cancer treatment] ... you grow a bond. You grow a trust .... I don't know. I feel like they were very 'professional' .... When they were done with their job, it was done. Time to move on." At the other end of the spectrum, a caregiver described her satisfaction with how her friend's physician communicated prognostic information: "Within the first month of her diagnosis, he looked me in the face ... and he said, 'Most people don't survive more than a year [with] this diagnosis at this level,' and his eyes were welling up with tears. He was so kind" (P036). Another caregiver offered the following advice to healthcare providers: "Don't shut off your feelings, you know, because there's just too many cold doctors out there that [are] just acting like they're robots" (P042).

### **Caregivers value providers whose communication focuses broadly on patients and caregivers' experiences.**

Just as they valued authenticity in provider communication, caregivers voiced strong appreciation for healthcare professionals whose communication focused on patients and caregivers as "whole people" both within and beyond the clinic. Caregiver P023 explained:

“I think sometimes the doctors, they’re just looking at numbers and ... test results, and ... even though they might have a good bedside manner ... they’re treating ... the illness. Whereas, sometimes ... the patient and the family need to be treated too.” Many caregivers discussed the importance of learning about patients and caregivers’ interests and experiences, as one caregiver (P019) described, “so [they] knew us personally ... more than just what the medical things were. That really meant ... a lot to us.”

Also included in this theme were caregiver statements emphasizing the importance of communication focused on patients and caregivers’ needs outside of the clinic. They repeatedly emphasized the importance of provider availability between scheduled visits to the cancer center, recalling feelings of frustration when their calls, emails, and other attempts at communication went unreturned. While the most commonly cited reason for attempting to contact healthcare providers outside of planned visits was a medical issue, some caregivers conceptualized provider support more broadly. For example, a participant (P057) who cited provider availability as the “biggest part” of good patient and family care explained, “Someone to talk to when you need to talk - that’s probably my most important thing .... Someone to maybe tell you you’re not the first one, you know? And [that] it is going to end.”

### **Caregivers value providers who are sensitive to unmet information needs.**

Almost universally, caregivers described an awareness of unmet information needs as an important component of effective communication. Unmet information needs were identified with regard to numerous issues and included financial questions, confusion about medical tests and treatments, and uncertainties pertaining to diagnosis and prognosis. Some caregivers expressed a more general confusion about multiple aspects of their patient’s care. For example, caregiver P069, in responding to an open-ended question about how providers could better support family members, stated, “I think they could do more of actually explaining what’s going on and exactly what steps they’re going to take [and] how they’re going to do treatment.” One caregiver (P043) distinguished between factual communication and communication that helped patients and caregivers understand what the facts meant: “You learn things as you go, but [it’s been hard] just being faced with the diagnosis and not having that information about ... what it means for [my husband and] what it means for the family members as far as ... quality of life and length of life and all of that.” Many caregivers reported that, when faced with uncertainty, they often turned to non-provider sources for information. One patient’s husband (P068) discussed learning about his wife’s prognosis from independent research. He explained, “[I know what to expect] from what I’ve read and research[ed], and then I kind of inject in what I hope.” In discussing how she solved caregiving problems, a mother caring for her adult daughter stated, “Sometimes I get on the internet and look things up just to see what their opinion is or what they would do” (P002). When asked what types of things she researched online, she responded, “Mostly what other kind of medication she could be on [to manage her symptoms].”

Some caregivers also commented on providers’ communication regarding patients’ unmet information needs, typically valuing the same qualities in provider-patient communication as they did in provider-caregiver communication. Caregiver P066 emphasized that providers



should accept responsibility for meeting the patient's information needs unless the patient prefers otherwise. To illustrate her point, she shared the story of her mother's surgery, which revealed that her mother's cancer was more advanced than previously thought: "I said [to the surgeon], 'Well, are you going to tell Mom?' and he goes, 'Well, you guys are going to tell her.'" While the recovery room nurses attempted to educate her mother, she later expressed confusion and needed to be re-informed by the caregiver. The caregiver concluded, "It would have been nice [to have] ... somebody to help talk to Mom because it was really hard for me to tell her, especially whenever I was going to be by myself."

### **Caregivers value providers who are responsive to the potentially different communication preferences of patients and caregivers.**

In several instances caregivers described the ways in which their information preferences differed from those of the patient. For example, caregiver P043 described wanting as much information as possible about her husband's illness in order to plan for the future. She explained that her husband, on the other hand, wanted minimal prognostic information. When asked if she was ever able to receive the information she desired, she replied, "Yes .... I stepped out in the hallway and said, 'I would like to know,' and someone was kind enough to just tell me." For other caregivers, however, their information preferences were closely aligned with those of the patient. When asked about their information preferences, these caregivers tended to use words like "we" and "us." One such caregiver (P059) recalled the day her husband opted to enroll in hospice: "Whenever the cancer doctor visited with us ... she [asked], 'Well, do you want details or do you want me to kind of skim over [the information]?' And my husband and I both said, 'No, we want details,' and the fact that she was extremely graphic on what to expect with and without chemo was very helpful."

## **Discussion**

The five themes detailed above can be summarized in a single, overarching theme. Simply put, family caregivers expressed a strong preference for person-centered communication, which they conceptualized as communication that helps healthcare providers meet the needs of patients and caregivers both as individuals and as an interdependent unit of care, and that acknowledges individuals' experiences beyond their prescribed roles of "cancer patient" and "caregiver." In several respects, this theme mirrors findings of other studies focused on provider-caregiver communication. For example, caregivers in Waldrop and colleagues'<sup>14</sup> research expressed satisfaction with communication that was compassionate, responsive, and dedicated, as did the caregivers in the present study. In addition, it is not difficult to imagine that caregivers who felt generally confused about their patient's cancer and its treatment would have endorsed a desire for information on how to communicate with providers or which questions are important to ask, as was true for caregivers enrolled in Longacre et al.'s research.<sup>15</sup> These study findings add to the existing literature in numerous ways as well, particularly with regard to the ways in which caregivers' information preferences may differ from those of the patient, and caregivers' appreciation for being acknowledged as an integral part of healthcare communication rather than, as caregiver P018 put it, "just sitting by."

Taken at face value, several of the findings generated in this study are somewhat unsurprising. For example, family caregivers wish to be paid attention to, to be respected, and to have their educational needs addressed. Responding to these preferences seemingly requires a very basic level of communicative competency, one that could reasonably be expected of any healthcare professional. Why, then, were these points repeatedly emphasized by family caregivers, who discussed them as noteworthy behaviors rather than an expected feature of healthcare communication? Greene and Adelman's<sup>20</sup> model of triadic communication in medical encounters provides a useful theoretical context through which to consider this question. Greene and Adelman assert that the addition of a third party introduces significant complexity into typical provider-patient communication. They suggest that the information needs of both the patient and caregiver must be addressed in triadic medical encounters, and that the provider must attend and express genuineness to both parties, noting each of their verbal and non-verbal communication, and providing information in a manner accessible to both. In addition, within communication triads the possibility exists that any two individuals will develop a so-called "coalition" to strengthen their communicative power in interactions with the third party,<sup>20</sup> a dynamic providers must carefully navigate to meet the needs of both patient and caregiver, avoiding "taking sides" and working to satisfy patients' and caregivers' sometimes conflicting wishes. Thus, despite the relatively straightforward manner in which caregivers discussed their communication preferences in this study, the reality for clinicians is that navigating triadic encounters requires a sophisticated level of communicative skill. The potential complexity of these interactions for providers should be the focus of future research that builds on this study of family caregivers' perspectives.

### **Implications for Psychosocial Providers**

The presence of a family caregiver or other companion is commonplace in cancer care; one study found that at least one companion was present in 86% of oncology visits during which "bad news" was discussed.<sup>21</sup> Thus, the findings reported here have clear implications for psychosocial oncology practice. Psychosocial providers and others on the cancer care team seeking to more intentionally support family caregivers can do so by offering both the patient and caregiver their undivided attention, balancing professionalism with genuineness in their communication. They can specifically acknowledge family caregivers during clinical interactions, inquiring about both patients and caregivers' wellbeing and coping efforts. They can create care delivery systems that are available to patients and caregivers during and outside of regularly scheduled appointments, and – with patients' permission – can assess and respect caregivers' potentially unique preferences regarding provision of information. Finally, they can appreciate the richness and complexity of patients and caregivers' lives before, during, and after their receipt of cancer care, offering support for their quality of life in both the short- and long-term, and can encourage their colleagues to do the same.

### **Limitations**

Several study limitations merit consideration. As with all secondary analyses, data analyzed in the present inquiry were limited to those collected during the original study, which was limited in geographic range and racial/ethnic diversity. Thus, it cannot be assumed that the present findings are transferable to all other settings or populations. Additionally noteworthy



is the fact that all data were obtained from family caregivers of patients who were receiving palliative care in some capacity. While these caregivers discussed their interactions with a broad range of cancer care providers, it is possible that their perspectives differed from those of caregivers whose patients did not receive palliative services. It is also possible that caregivers who received the intervention that was tested in the RCT were influenced in a way that affected their communication with providers, thereby shaping the responses they gave when interviewed. Further, the duration of the interviews analyzed in this study was relatively short (mean = approximately 30 minutes), precluding a more in-depth exploration of the issues raised here. Communication appears to be a sufficiently salient topic among family caregivers to warrant additional research; future studies would benefit from primary data collection focused specifically on communication, with lengthier interviews of key informants. Finally, because the original study had concluded prior to this analysis, researchers were unable to engage study participants in member checking,<sup>22</sup> which would have served as an additional confirmation of the findings' validity.

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**Table 1**

## Participant Characteristics (N = 63)

| Characteristic   | <i>n</i> (%) <sup>a</sup> |
|--|---------------------------|
| Age, mean ( <i>SD</i> )  | 52.9 (12.6)               |
| Gender   |                           |
| Female   | 45 (71.4)                 |
| Male   | 18 (28.6)                 |
| Relationship to Patient <sup>b</sup>                                     |                           |
| Spouse/Long-term Partner   | 34 (52.3)                 |
| Adult Child/Grandchild   | 19 (29.2)                 |
| Sibling  | 5 (7.7)                   |
| Parent   | 3 (4.6)                   |
| Other (e.g., Friend, Nephew)   | 4 (6.2)                   |
| Patient Cancer Primary Site/Type <sup>b</sup>                            |                           |
| Colorectal   | 12 (18.5)                 |
| Lung   | 10 (15.4)                 |
| Breast   | 8 (12.3)                  |
| Gynecologic  | 6 (9.2)                   |
| Liver  | 4 (6.2)                   |
| Pancreatic   | 4 (6.2)                   |
| Melanoma   | 3 (4.6)                   |
| Prostate   | 3 (4.6)                   |
| Other (sites/types with <i>n</i> = 2; e.g., Head and Neck, Mesothelioma) | 15 (23.1)                 |
| Caregiver Ethnicity  |                           |
| Latinx   | 1 (1.6)                   |
| Non-Latinx   | 62 (98.4)                 |
| Race   |                           |
| Caucasian  | 61 (96.8)                 |
| Native American  | 2 (3.2)                   |

<sup>a</sup>Unless otherwise noted; Percentages may not total 100 due to rounding.

<sup>b</sup>Two participants cared for two different patients, resulting in 65 responses to these items.

**Table 2****Interview Guide<sup>a</sup>**

- 
1. What are some of the problems you face when caring for someone with cancer?
  2. Who and/or what do you find helpful when facing caregiving problems?
  3. How do you solve caregiving problems?
  4. What recommendations do you have for healthcare providers who want to support family caregivers? Are there things your healthcare team currently does that are helpful? Do you have suggestions to help your team provide even better support to family caregivers?
  5. Now I'd like you to think specifically about your palliative care team. That includes [palliative nurse practitioner name], [palliative physician name], [palliative social worker name], [other palliative care team member names, as applicable]. Are there things they currently do that are helpful to you as a caregiver? Do you have suggestions to help them provide even better support to family caregivers?
  6. How, if at all, did members of your healthcare team talk to you about what to expect with regard to [patient name]'s cancer over time? Who discussed that with you? When? What did the discussion entail? Did you have an idea of what changes to expect in the short-term? In the long-term? How did it feel to be a part of those discussions? What went well in those discussions? What was more difficult?
  7. Some people like to have a lot of information about what to expect with regard to a person's cancer and how it might change over time. Others prefer to take things day-by-day. What's your preference? Why do you think that is? How, if at all, has your preference changed over time?
  8. Sometimes healthcare providers have conversations with patients and/or their caregivers about what types of care they would want if their cancer became very advanced. That discussion may also include considering who would be the best person to make healthcare-related decisions for the patient if they were to become too sick to make those decisions for themselves. Have you or the person you care for discussed anything like that with your healthcare team? [If yes] Would you please tell me about that conversation? [If no] How do you think you would feel about having a conversation like that?

<sup>a</sup>Questions 1–4 were asked of all study participants. Questions 5–8 were asked of the final half

( $n = 31$ ). Questions focused on evaluation of the intervention delivered in the parent study are omitted here, as they did not address the present study's research question.