



Published in final edited form as:

Patient Educ Couns. 2019 May ; 102(5): 909–915. doi:10.1016/j.pec.2018.12.014.

When chemotherapy fails: Emotionally charged experiences faced by family caregivers of patients with advanced cancer

Rachel A. Rodenbach, MD^a, Sally A. Norton, PhD, RN^b, Marsha N. Wittink, MD^b, Supriya Mohile, MD MS^b, Holly G. Prigerson, PhD^c, Paul R. Duberstein, PhD^{b,d,e}, and Ronald M. Epstein, MD^{b,d}

^aUniversity of Pittsburgh Medical Center, 3459 5th Ave, Pittsburgh, Pennsylvania, USA 15213

^bUniversity of Rochester Medical Center, 601 Elmwood Ave, Rochester, New York, USA 14642

^cWeill Cornell Medicine, 413 E 69th St, New York City, New York, USA 10021

^dCenter for Communication and Disparities Research, 1381 South Ave, Rochester, New York, USA 14620

^eRutgers School of Public Health, 683 Hoes Lane West, Piscataway, New Jersey, USA 08854

Abstract

Objective: To explore family caregivers' emotional experiences while caring for patients with advanced cancer and navigating distressing information, awareness of dying, and difficult decisions.

Methods: Qualitative descriptive study of semi-structured interviews with 92 bereaved caregivers of patients with advanced cancer. Interviews explored caregivers' experiences as patients transitioned out of active cancer treatment and neared the end of life.

Results: Included in caregivers' characterization of this transition time were three particularly emotionally charged experiences. The first occurred when caregivers felt jolted into awareness that patients were dying. They were startled to realize that patients would die sooner than expected; some expressed frustration that they had not been adequately warned. In the second, caregivers felt conflicted when involved in decisions that pitted patients' preferences against what caregivers felt patients needed, resulting in ambivalence, guilt, and grief. Thirdly, caregivers who felt they did their best for patients expressed fulfillment and gratitude.

Conclusion: Caregivers of patients with advanced cancer face unique, emotionally charged experiences that can lead to distress and affect care at the end of life.

Corresponding author at: Rachel A. Rodenbach, University of Pittsburgh Medical Center Montefiore Hospital, N-715, 200 Lothrop Street, Pittsburgh, PA 15213, Phone: (507) 254-4976, Fax: (585) 473-2245, rachel.a.cameron@gmail.com; rodenbachra@upmc.edu.

None of the authors has any conflicts of interest or financial disclosure influencing the contents of this paper.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Practice Implications: Awareness of these situations may help oncology teams to provide sufficient guidance and support, partner with caregivers to clarify patients' needs, and deliver higher quality care.

Keywords

caregivers; end of life; cancer; communication; decision making; qualitative research

1. Introduction

Cancer, like other serious illnesses, affects not only patients but also their family caregivers [1]. In addition to delivering physical care, family caregivers of patients with advanced cancer provide emotional and social support, help manage symptoms, and communicate with clinicians. These caregivers, while trying to prioritize patients' preferences, often are intimately involved in decision making [2]. As patients' illnesses progress, caregivers often need informational, social, and psychological support to help them make decisions in clinically uncertain situations and manage their own fears about patients' clinical decline, feelings of failure and regret, and their own health [3-7].

The significant physical and emotional stress experienced by family caregivers of patients with advanced cancer can have adverse consequences, including worse physical health, sleep disturbances, clinical depression and anxiety, financial strain, and overall poor quality of life [3, 8-12]. As the mental and physical health of caregivers and patients is interrelated, caregivers' stress often worsens alongside patients' declining functional status [13, 14]. On the other hand, many caregivers experience several positive aspects of caregiving, including the sense of personal growth and enhanced relationships [15].

While adverse effects of caregiver burden and stress have been well-studied, to our knowledge no studies have looked specifically at caregivers' emotional experiences while integrally involved in caring for patients and witnessing the ravages of end stage disease. Specifically, caregivers encounter challenges as they navigate distressing information received from clinicians and patients, awareness of dying, decisions amid uncertainty, and competing obligations. Because many patients, caregivers, and clinicians might not explicitly acknowledge these challenges, this analysis explored caregivers' affectively charged experiences in greater depth. Specifically, we sought to develop a better understanding of the unique, emotionally intense situations encountered by caregivers of patients with advanced cancer at the end of life.

2. Methods

Data are from the Values and Options in Cancer Care (VOICE) study, a National Cancer Institute-sponsored multi-site cluster randomized controlled trial (RCT) designed to test a combined intervention to facilitate communication and decision making among oncologists, patients with advanced cancer, and their caregivers. Methodologic details and results from this RCT's primary analysis are described elsewhere [16, 17]. All protocols were approved by each site's Research Subjects Review Board.

Semi-structured interviews with recently bereaved caregivers were embedded in the RCT. Interviews were designed to elicit caregivers' perspectives about how patients transitioned from active cancer treatment to hospice [18]. Patients in the RCT had been eligible to participate if they were age 21 or older, able to understand spoken English and provide consent, and had either stage IV non-hematologic cancer or stage III cancer and whose oncologist "would not be surprised" if the patient died within 12 months [19]. Meanwhile, caregivers, who patients identified as a "family member, partner, or friend who is involved with your health care issues," were prospectively identified and enrolled in this study. Participants were enrolled from August 2012 to June 2014 and followed until October 2015. As part of the RCT, each patient and caregiver randomized to the intervention arm participated in a coaching intervention designed to identify questions to address with the oncologist and facilitate communication. Oncologists randomized to the intervention arm participated in a tailored educational intervention involving standardized patient instructors. Later, caregivers from both intervention and control arms participated in a one-on-one, semi-structured interview lasting between 15 and 45 minutes approximately seven to eight weeks after patients died. Interviewers were research assistants trained in qualitative interviewing well-known to participants due to previous interactions in the clinical trial. Interviewers' questions explored caregivers' experiences and perceptions of treatment decision making, patients' transitions out of active cancer treatment, and experiences of care during patients' last month of life (Supplemental Material). These interviews were audio-recorded, transcribed, de-identified, and entered into Atlas.ti 7.0 for data management.

In the primary qualitative data analysis, we characterized patterns of transition away from disease-directed cancer treatment at the end of life, using a multi-phased coding approach that allowed for both pre-specified and emergent domains [18]. For this study, we used a similar multi-phased approach focused on an emergent domain, the affective experience of caregivers. During phase 1, we coded pre-specified domains, employed open coding to identify emergent domains, and developed a provisional coding scheme. During the next phase we coded, analyzed, and compared all transcripts across intervention and control groups. During the third phase of the analysis, we focused on one of the emergent domains in the data, the emotional experience of caregivers in response to patients' experiences, reconciliation of differing perspectives and needs, decisions made, amount of clinical information received, level of understanding of patients' illness, and competing interests. During this phase, one team member (RR) examined transcripts to focus on the affective language caregivers used to describe their experiences, including both negative emotions (e.g., grief, denial, fright, confusion, regret) and positive emotions (e.g. gratitude, peace). In an iterative fashion, these affective descriptions were identified, categorized, and discussed with other team members (SN, RE) to arrive at a final coding scheme which we applied to all the transcripts (Supplementary Material). We used negative case analyses to refine our understanding of emerging patterns and an audit trail. Data analysis continued until similar instances were repeatedly identified and coded and no new themes emerged, at which time saturation was achieved.

3. Results

Of the 194 caregivers in the VOICE study, 125 became bereaved, 98 of whom participated in the postmortem semi-structured interview. The remaining caregivers were lost to follow up (19), withdrew from participation (4), or were unable to be scheduled within the follow-up time frame (4). The final study sample consisted of 92 caregivers, the point of data saturation (Tables 1 and 2).

Many family caregivers described circumstances leading to intense, conflicting feelings. Here, we focus on three sets of situations that were particularly emotionally charged, as described in turn below. Caregivers' relationship to the patient is indicated in parentheses.

3.1 Jolted by awareness of dying

Some caregivers reported knowing patients were dying as they watched them physically decline, with resulting sadness, resignation, wistful acceptance, and lack of surprise as patients became even sicker. However, others described a feeling of being jolted into awareness that patients were dying. These caregivers came to a more abrupt realization that patients would die and reported surprise that patients would die sooner than they had expected. Their awareness was prompted by either witnessing an increasingly rapid decline or being informed by clinicians that patients had entered a new phase in the illness trajectory (Table 3). These caregivers recounted moving from an abstract sense that the patients would die at an unspecified time to a startled awareness that the patients would die soon. Several described this previous state of knowing yet not being aware: *"I knew deep down inside [Patient's death] was getting close, but I had no idea it was gonna be that close"* (CG117, wife). Many caregivers mentioned that they had been told patients' prognoses previously but compartmentalized this knowledge, sometimes to continue *"hoping for miracles"* (CG116, wife) that patients would beat the odds. Meanwhile, some had recognized patients' worsening functional status but ignored it; as described by one (CG7, male other), *"you, maybe like an ostrich, stick your head in the sand and think well, he'll come back."* Because of this abrupt awareness that patients were nearing death, caregivers often felt increased shock, disbelief, and anticipatory grief.

Some caregivers who had not known that patients were dying believed they had not been adequately informed or warned (Table 3). Most described intense bewilderment, sorrow, guilt, and regret when they later became aware. In some cases, caregivers expressed resentment towards clinicians for not realistically discussing patients' expected course or all potential management options, leading to later frustration and anger at the oncology team. Many wished the oncologists *"would have just told us how devastating the chemo could be"* (CG124, brother). In hindsight caregivers felt that the burdens of chemotherapy exceeded their benefits and regretted that patients had not stopped chemotherapy and other treatments sooner. As one (CG70, sister) said, *"even if [off treatment you get] three weeks of good quality, it's better than six months of none"* on treatment. In a few cases, patients themselves kept important information that the oncology team had told them about disease progression and prognosis from caregivers, leaving caregivers unprepared to anticipate the patient's decline and to take on additional roles and responsibilities.

Caregivers who felt inadequately warned that patients were dying reported feeling inadequately prepared to be surrogate decision-makers. They also felt overwhelmed by the physical care that patients needed, emotionally taxed from watching patients decline, and cognitively overloaded with decisions regarding patients' care and prioritizing patients' needs. As described by one who was surprised by the patient's "*very rapid descent*" (CG164, husband), the health team could have done more to get "*the caregiver ready to do the right thing by the ill person, more than just crutches or support for the person who is emotional wounded – more what to do at what point.*" Some second-guessed themselves and worried about how to best care for their loved ones.

3.2 Caught in the middle of decisions

Caregivers reported feeling conflicted when caught in the middle of decisions that pitted patients' preferences against caregivers' own thoughts about what was best for patients, leading to angst about how or when to intervene. Most of the time caregivers explicitly supported patients' decisions, even when they personally disagreed, as they felt that they should champion patients' wishes: "*I just always told [Patient] if that's what you want, I'm behind you 100%*" (CG3, daughter). Even as patients declined further, many caregivers recalled continuing to advocate intently for what patients had wanted and derived a sense of peace of mind in doing so (see next section). However, some caregivers felt distress and anguish when they tried to reconcile conflicts between patients' preferences and their own beliefs (Table 4).

When patients became too sick for chemotherapy yet would not accept hospice referrals, some caregivers described disagreeing so strongly that they considered making referrals despite patients' objections. Particularly poignant were situations in which caregivers provided around-the-clock care yet felt helpless in relieving patients' suffering by themselves and worried about their safety; these situations "*had just gotten too hard*" for caregivers to manage on their own without hospice (CG138, wife). Some described difficult conversations to coax patients into changing their minds about hospice care while preserving patients' sense of autonomy. Few caregivers felt comfortable getting hospice involved without patients' approval; as one (CG45, female other) said, "*we wanted it so much to be her decision to go. We didn't want to have to make that decision for her.*" However, even after making the transition to hospice, a few caregivers described feeling lingering indecision and guilt.

Additionally, when patients who previously were described as "fighters" lost capacity to make decisions, some caregivers struggled with the incongruity between patients' weakened states and their prior resolve to continue aggressive, life-prolonging treatments. These caregivers reported feeling uncomfortable and overwhelmed by having to decide whether to continue treatments patients had wanted, particularly when other family members or caregivers were not physically or emotionally present to share the burden. As one (CG172, daughter) reflected, "*It was only me, you know, making these decisions... I hope that these were the right decisions to make.*"

In contrast, a few caregivers described feeling distressed when a patient had preferred a less aggressive approach. As these patients became sicker, caregivers felt heightened

helplessness and sorrow, which occasionally incited frantic, impulsive decisions to do more. In one striking example, a caregiver disclosed how he went against a patient's wishes and allowed her to be intubated, recognizing that it was due to his own panic watching her struggle. Meanwhile, some grieving caregivers came to recognize that doing the best thing for patients meant letting go: "you have to ask yourself am I keeping them alive for them or am I just being selfish and I don't want to lose them so I'm gonna just keep them here to keep them here" (CG90, husband).

3.3 Finding gratitude, peace, and purpose

Despite grief and distress, many caregivers described experiences of gratitude, fulfillment, and peace from spending time with patients and knowing that they were doing their best for them (Table 5). Often other family members, friends, and hospice staff helped caregivers shift towards this more positive focus. Caregivers recounted how these individuals provided anticipatory guidance and support and enabled them to tend to their own physical and mental health so that they could reclaim a sense of purpose while caring for the patient. With such support, these caregivers felt better equipped to facilitate patients' own sense of well-being and peace.

For caregivers who were able to refocus in this way, the experience of caring for dying patients became both more bearable and more gratifying. Some expressed appreciation and joy for the chance to strengthen their relationship with patients and spend quality time together. Others found peace while reflecting on past life experiences and believing patients had lived their lives well. These caregivers described accepting that it was patients' time to die and sometimes even felt that death itself was desirable because it would relieve patients' suffering: "I was very happy at home with [Patient] and he was, too. He knew he was dying and we all, the whole family, did. And you get to the point where you want him to die" (CG77, wife).

These caregivers also described deriving purpose and satisfaction from advocating for and carrying out patients' wishes at the end of life, whether regarding location of death, pain management, or other aspects of care. Ensuring that patients' wishes were honored often required much self-sacrifice; knowing they had done all they could to make patients' last weeks of life high quality led to a sense of accomplishment and peace. As one (CG22, husband) said, "I felt like for a while I was doing hospice care by myself, you know, and not knowing what I was doing and stuff. But that was her wish. So ... I'm gonna do it."

4. Discussion and Conclusion

4.1 Discussion

Family caregivers of patients with advanced cancer are often actively involved in many aspects of care and advocate intently for patients. In this study, we identified three particularly emotionally charged situations these caregivers experience while caring for patients with advanced cancer and navigating varying levels of awareness, tension between their and patients' perspectives, and ambiguous clinical circumstances. When oncology teams – comprised of oncologists as well as palliative care specialists, nurses, social

workers, and behavioral health specialists – can more clearly understand situations that trigger heightened emotions in caregivers, they can proactively support caregivers, mitigate adverse effects of caregiving, and ultimately facilitate the most appropriate care for patients.

Our study illustrates the complexity and consequences of caregiver decision making that arise when patients' clinical conditions are incongruous with enacting their previously stated wishes, adding nuance to previous findings documenting that caregivers generally follow patients' wishes even when they disagree [20]. Caregivers often felt intense uncertainty and guilt when forced by clinical circumstances and patients' changing needs to consider and ultimately go against patients' previously stated wishes. Especially in the situations we described, caregivers may need to be warned that patients too may feel ambivalent; patients' preferences may fluctuate over short periods of time [21]; and unanticipated events may mandate change of course as patients' suffering worsens.

Past studies have shown that patients and caregivers often have optimistic estimates of prognosis [22-25] and that preservation of hope in the face of realism is vital to patients' and families' day-to-day functioning [26-28]. Prior studies indicate that physicians often misrepresent (intentionally or unintentionally) patients' prognosis, contributing to patients' and caregivers' misunderstandings [29]. However, other unpublished analyses from the VOICE study demonstrated that physicians' prognosis estimates were remarkably accurate [30]. Many caregivers in our study reported having been informed about prognosis yet remained unaware of patients' impending death [31], did not quite believe the information, or compartmentalized those conversations, in attempts to preserve hope for longer survival. This observation provides an intricate understanding of caregivers' management of prognostic information and the paradox that patients, caregivers, and clinicians report that such discussions had occurred yet maintain markedly discordant prognostic estimates. This dynamic also helps to explain caregivers' emotional distress, shock, and grief when they realized patients were dying sooner than they had come to expect. While unexpected patient death can lead to higher rates of depression, poor physical health, and even death in their caregivers [32, 33], our study demonstrates that some caregivers experience extreme distress even when death is "sooner than expected" but not "unexpected." Future research could clarify how oncology teams can best identify those caregivers who "know yet are not aware" of patients' imminent deaths and appropriately intervene.

The stories of caregivers who felt misled, abandoned, and betrayed due to not having been adequately informed were troubling. Clinicians may underestimate the degree to which their communication about prognosis is unclear, vague, misinterpreted, or forgotten [34-39]. While clinicians are obligated not to inform caregivers without patients' consent, caregivers may desire more information than patients themselves about patients' clinical status [38, 40, 41]. Clinicians need to be mindful to discuss treatment options realistically, reassess clinical status at each visit, and avoid deliberately using words that can be easily misinterpreted.

While navigating distressing situations, caregivers also often derived peace, fulfillment, and connection. By delivering adequate, honest information, assisting in decision making, and remaining emotionally engaged, clinicians can help improve patients' and caregivers' quality of life and ability to cope [42, 43]. Moreover, recognition of situations that can lead

to intense emotions and anguish may help clinicians identify not only patients but also caregivers who are struggling the most and in need of psychologic or social support. Studies have shown that patients and families benefit from earlier referral to palliative care and hospice [44, 45], and that palliative care specialists' emphasis on symptom control, treatment decisions, and advanced care planning lead to higher quality end-of-life care [46]. Multifaceted oncology teams that include palliative care clinicians can also assess caregivers' informational and affective needs, foster open communication, and provide sufficient anticipatory guidance [3, 10].

Strengths of this study include in-depth analysis of caregiver experiences from interviews shortly after the patient's death, rigorous qualitative research design, and frequent team discussions. A number of limitations also are noted. Firstly, in this qualitative analysis we considered caregivers as a group, regardless of whether they were spouses (the majority), children, parents, or siblings of patients. While there may be differences in emotional experiences depending upon the caregiver's relationship to the patient [47], our study focused on describing the range of caregiver responses rather than differences among groups. Nonetheless, the demographic makeup of this study (mostly Caucasians with some level of higher education) potentially limits its generalizability to more diverse populations. Additionally, the interviews were not designed a priori to directly address the research questions in this secondary analysis. Finally, interviews were conducted nearly two months after the patient died, potentially leading to recall bias and omission or inflation of past events. The grieving process itself may also have impacted caregivers' way of recalling experiences [48].

4.2 Conclusion

By focusing on unique experiences of caregivers, this study identified multiple emotionally intense moments caregivers may endure while caring for patients with advanced cancer. Caregivers faced dual stresses of advocating for patients' needs and preferences while experiencing anticipatory grief and loss. While some of these stresses led to feelings of helplessness, especially when patients' and caregivers' perspectives did not align, many caregivers in our study reported a sense of attainment and peace. Caregiver well-being is associated with patient-perceived quality of care [49]; tending to caregivers' emotional experiences and partnering with caregivers to understand patients' needs may be an important vehicle for higher quality patient care.

4.3 Practice Implications

Oncology teams may help alleviate caregivers' distress by providing sufficient anticipatory guidance and support. They can anticipate emotionally charged experiences and caregivers' needs for information (e.g. what is likely to happen at the end of life), encourage patients and their families to plan ahead for worst-case scenarios, and provide support to caregivers both before and after patients have died [33]. Given that caregivers experience heightened distress when a patient's death is sooner than expected, earlier, more explicit discussions of caregivers' roles in decision making may help mitigate later distress. Clinicians may also benefit from communication training focused on addressing the "fighter" mentality in the setting of worsening patient quality of life – in particular, helping patients and their

caregivers to change treatment course while respecting integral parts of patients' identities [50].

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding: This work was supported by the National Institutes of Health/National Cancer Institute (R01CA140419, R01CA168387, R21CA218313).

References

- [1]. Edwards B, Clarke V, The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety, *Psychooncology* 13 (2004) 562–576. [PubMed: 15295777]
- [2]. Laidsaar-Powell R, Butow P, Bu S, Charles C, Gafni A, Fisher A, Juraskova I, Family involvement in cancer treatment decision-making: a qualitative study of patient, family, and clinician attitudes and experiences, *Patient Educ. Couns* 99 (2016) 1146–1155. [PubMed: 26873544]
- [3]. Butow PN, Price MA, Bell ML, Webb PM, deFazio A, Friedlander M, A.O.C.S. Group, A.O.C.S.Q.O.L.S. Investigators, Caring for women with ovarian cancer in the last year of life: a longitudinal study of caregiver quality of life, distress and unmet needs, *Gynecol. Oncol* 132 (2014) 690–697. [PubMed: 24423880]
- [4]. Hashemi M, Irajpour A, Taleghani F, Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients, *Support. Care Cancer* 26 (2018) 759–766.
- [5]. Sklenarova H, Krümpelmann A, Haun MW, Friederich HC, Huber J, Thomas M, Winkler EC, Herzog W, Hartmann M, When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors, *Cancer* 121 (2015) 1513–1519. [PubMed: 25677095]
- [6]. Kirk P, Kirk I, Kristjanson LJ, What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study, *Br. Med. J* 328 (2004) 1343. [PubMed: 15151964]
- [7]. Eriksson E, Lauri S, Informational and emotional support for cancer patients' relatives., *Eur. J Cancer Care* 9 (2000) 8–15.
- [8]. Cameron JI, Franche RL, Cheung AM, Stewart DE, Lifestyle interference and emotional distress in family caregivers of advanced cancer patients, *Cancer* 94 (2002) 521–527. [PubMed: 11900237]
- [9]. Hsu T, Loscalzo M, Ramani R, Forman S, Popplewell L, Clark K, Katheria V, Feng T, Strowbridge R, Rinehart R, Smith D, Matthews K, Dillehunt J, Hurria A, Factors associated with high burden in caregivers of older adults with cancer, *Cancer* 120 (2014) 2927–2935. [PubMed: 24898093]
- [10]. Northouse L, Williams AL, Given B, McCorkle R, Psychosocial care for family caregivers of patients with cancer, *J. Clin. Oncol* 30 (2012) 1227–1234. [PubMed: 22412124]
- [11]. Ostlund U, Wennman-Larsen A, Persson C, Gustavsson P, Wengström Y, Mental health in significant others of patients dying from lung cancer, *Psychooncology* 19 (2010) 29–37. [PubMed: 19253315]
- [12]. Vanderwerker LC, Laff RE, Kadan-Lottick NS, McColl S, Prigerson HG, Psychiatric disorders and mental health service use among caregivers of advanced cancer patients, *J. Clin. Oncol* 23 (2005) 6899–6907. [PubMed: 16129849]
- [13]. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, Willan A, Viola R, Coristine M, Janz T, Glossop R, Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers, *Can. Med. Assoc. J* 170 (2004) 1795–1801. [PubMed: 15184333]

- [14]. Kershaw T, Ellis KR, Yoon H, Schafenacker A, Katapodi M, Northouse L, The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time, *Ann. Behav. Med* 49 (2015) 901–911. [PubMed: 26489843]
- [15]. Li Q, Loke AY, The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research, *Psychooncology* 22 (2013) 2399–2407. [PubMed: 23712938]
- [16]. Epstein RM, Duberstein PR, Fenton JJ, Fiscella K, Hoerger M, Tancredi DJ, Xing G, Gramling R, Mohile S, Franks P, Kaesberg P, Plumb S, Cipri CS, Street RL, Shields CG, Back AL, Butow P, Walczak A, Tattersall M, Venuti A, Sullivan P, Robinson M, Hoh B, Lewis L, Kravitz RL, Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: the VOICE randomized clinical trial, *JAMA Oncol.* 3 (2017) 92–100. [PubMed: 27612178]
- [17]. Hoerger M, Epstein RM, Winters PC, Fiscella K, Duberstein PR, Gramling R, Butow PN, Mohile SG, Kaesberg PR, Tang W, Plumb S, Walczak A, Back AL, Tancredi D, Venuti A, Cipri C, Escalera G, Ferro C, Gaudion D, Hoh B, Leatherwood B, Lewis L, Robinson M, Sullivan P, Kravitz RL, Values and options in cancer care (VOICE): study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers, *BMC Cancer* 13 (2013) 188. [PubMed: 23570278]
- [18]. Norton SA, Wittink MN, Duberstein PR, Prigerson HG, Stanek S, Epstein RM, Family caregiver descriptions of stopping chemotherapy and end-of-life transitions, *Support. Care Cancer* (2018). 10.1007/s00520-018-4365-0
- [19]. Moss AH, Lunney JR, Culp S, Auber M, Kurian S, Rogers J, Dower J, Abraham J, Prognostic significance of the "surprise" question in cancer patients, *J. Palliat. Med* 13 (2010) 837–840. [PubMed: 20636154]
- [20]. Wijnhoven MN, Terpstra WE, van Rossem R, Haazer C, Gunnink-Boonstra N, Sonke GS, Buiting HM, Bereaved relatives' experiences during the incurable phase of cancer: a qualitative interview study, *BMJ Open* 5 (2015) e009009 10.1136/bmjopen-2015-009009.
- [21]. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D, Will to live in the terminally ill, *Lancet* 354 (1999) 816–819. [PubMed: 10485723]
- [22]. Gramling R, Fiscella K, Xing G, Hoerger M, Duberstein P, Plumb S, Mohile S, Fenton JJ, Tancredi DJ, Kravitz RL, Epstein RM, Determinants of patient-oncologist prognostic discordance in advanced cancer, *JAMA Oncol.* 2 (2016) 1421–1426. [PubMed: 27415765]
- [23]. Enzinger AC, Zhang B, Schrag D, Prigerson HG, Outcomes of prognostic disclosure: associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer, *J. Clin. Oncol* 33 (2015) 3809–3816. [PubMed: 26438121]
- [24]. El-Jawahri A, Traeger L, Kuzmuk K, Eusebio J, Vandusen H, Keenan T, Shin J, Gallagher ER, Greer JA, Pirl WF, Jackson VA, Ballen KK, Spitzer TR, Graubert TA, McAfee S, Dey B, Chen YB, Temel JS, Prognostic understanding, quality of life and mood in patients undergoing hematopoietic stem cell transplantation, *Bone Marrow Transplant.* 50 (2015) 1119–1124. [PubMed: 25961772]
- [25]. Trevino KM, Maciejewski PK, Shen MJ, Prigerson HG, Mohile S, Kamen C, Epstein RM, Duberstein P, How much time is left? Associations between estimations of patient life-expectancy and quality of life in patients and caregivers, Under review.
- [26]. Clayton JM, Butow PN, Arnold RM, Tattersall MH, Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers, *Cancer* 103 (2005) 1965–1975. [PubMed: 15789360]
- [27]. Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leigh N, MacLeod C, MacLeod C, Tattersall MH, Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis, *J. Clin. Oncol* 23 (2005) 1278–1288. [PubMed: 15718326]
- [28]. Wenrich MD, Curtis JR, Shannon SE, Carline JD, Ambrozy DM, Ramsey PG, Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death, *Arch. Intern. Med* 161 (2001) 868–874. [PubMed: 11268231]
- [29]. Christakis NA, Lamont EB, Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study, *Br. Med. J* 320 (2000) 469–472. [PubMed: 10678857]

- [30]. Malhotra K, DeMartini JM, Fenton JJ, Epstein RM, Duberstein PR, Cipri C, Tancredi D, Xing G, Kaesberg P, Kravitz R, Hopes for advanced cancer treatment: prognostic accuracy of patients, caregivers and oncologists in advanced cancer, unpublished.
- [31]. Hoff L, Hermerén G, Information from physicians and retention of information by patients - obstacles to the awareness of patients of progressing disease when life is near the end, *BMC Palliat. Care* 7 (2008) 2. [PubMed: 18307800]
- [32]. Burton AM, Haley WE, Small BJ, Bereavement after caregiving or unexpected death: effects on elderly spouses, *Aging Ment. Health* 10 (2006) 319–326. [PubMed: 16777661]
- [33]. Hui D, Unexpected death in palliative care: what to expect when you are not expecting, *Curr. Opin. Support. Palliat. Care* 9 (2015) 369–374. [PubMed: 26509862]
- [34]. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH, Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *J. Palliat. Med* 8 (2005) 1176–1185. [PubMed: 16351531]
- [35]. Fried TR, Bradley EH, O'Leary J, Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians, *J. Am. Geriatr. Soc* 51 (2003) 1398–1403. [PubMed: 14511159]
- [36]. Harrop E, Morgan F, Byrne A, Nelson A, "It still haunts me whether we did the right thing": a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers, *BMC Palliat. Care* 15 (2016) 92. [PubMed: 27825330]
- [37]. Jenkins V, Solis-Trapala I, Langridge C, Catt S, Talbot DC, Fallowfield LJ, What oncologists believe they said and what patients believe they heard: an analysis of phase I trial discussions, *J. Clin. Oncol* 29 (2011) 61–68. [PubMed: 21098322]
- [38]. Park EM, Check DK, Yopp JM, Deal AM, Edwards TP, Rosenstein DL, An exploratory study of end-of-life prognostic communication needs as reported by widowed fathers due to cancer, *Psychooncology* 24 (2015) 1471–1476. [PubMed: 25655038]
- [39]. Rodenbach RA, Rodenbach KE, Tejani MA, Epstein RM, Relationships between personal attitudes about death and communication with terminally ill patients: how oncology clinicians grapple with mortality, *Patient Educ. Couns* 99 (2016) 356–363. [PubMed: 26519993]
- [40]. Csikai EL, Bereaved hospice caregivers' perceptions of the end-of-life care communication process and the involvement of health care professionals, *J. Palliat. Med* 9 (2006) 1300–1309. [PubMed: 17187538]
- [41]. Steinhäuser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, Tulskey JA, Preparing for the end of life: preferences of patients, families, physicians, and other care providers, *J. Pain Symptom Manage.* 22 (2001) 727–737. [PubMed: 11532586]
- [42]. Epstein RM, Back AL, Responding to Suffering, *JAMA* 314 (2015) 2623–2624. [PubMed: 26720023]
- [43]. Woodman C, Baillie J, Sivell S, The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence, *BMJ Support. Palliat. Care* 6 (2016) 418–429.
- [44]. Dionne-Odom JN, Azuero A, Lyons KD, Hull JG, Tosteson T, Li Z, Frost J, Dagnev KH, Akyar I, Hegel MT, Bakitas MA, Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: outcomes from the ENABLE III randomized controlled trial, *J. Clin. Oncol* 33 (2015) 1446–1452. [PubMed: 25800762]
- [45]. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ, Early palliative care for patients with metastatic non-small-cell lung cancer, *N. Engl. J. Med* 363 (2010) 733–742. [PubMed: 20818875]
- [46]. Hoerger M, Greer JA, Jackson VA, Park ER, Pirl WF, El-Jawahri A, Gallagher ER, Hagan T, Jacobsen J, Perry LM, Temel JS, Defining the elements of early palliative care that are associated with patient-reported outcomes and the delivery of end-of-life care, *J. Clin. Oncol* 36 (2018) 1096–1102. [PubMed: 29474102]
- [47]. Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, Rahbar M, Burden and depression among caregivers of patients with cancer at the end of life, *Oncol. Nurs. Forum* 31 (2004) 1105–1117. [PubMed: 15547633]

- [48]. Bentley B, O'Connor M, Conducting research interviews with bereaved family carers: when do we ask? *J. Palliat. Med* 18 (2015) 241–245. [PubMed: 25517136]
- [49]. Litzelman K, Kent EE, Mollica M, Rowland JH, How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways, *J. Clin. Oncol* 34 (2016) 3554–3561. [PubMed: 27573657]
- [50]. Molden DC, Dweck CS, Finding "meaning" in psychology: a lay theories approach to self-regulation, social perception, and social development, *Am. Psychol* 61 (2006) 192–203. [PubMed: 16594836]

Highlights

- Caregivers of patients with advanced cancer have emotionally charged experiences.
- Many caregivers abruptly realized that patients would die sooner than expected.
- These caregivers believed they had not been fully warned and felt increased grief.
- Caregivers felt conflicted when forced to make decisions against patients' wishes.
- Those who felt they did their best for patients experienced peace and gratitude.

Table 1.

Caregiver demographics

Caregivers (n=91*)	n (%)
Caregiver age (mean +/- STD, range)	64 +/- 12.1, 23-84
Race	
White	79 (87)
Non-white	12 (13)
Gender	
Female	61 (67)
Male	30 (33)
Education	
High school or less	23 (25)
Some college or more	68 (75)
Income	
\$20,000 or less	16 (18)
\$20,001 to \$50,000	28 (31)
\$50,001 to \$100,000	30 (33)
Over \$100,000	5 (5)
Missing	12 (13)
Relationship to patient	
Committed/married	59 (65)
Parent or adult child	13 (14)
Sibling	10 (11)
Other	9 (10)
Prior randomization during RCT	
Intervention	47 (52)
Control	44 (48)
Cancer type of patient	
Breast	17 (19)
Colorectal	8 (9)
Lung	23 (25)
Prostate	10 (11)
Pancreatic	12 (13)
Other GI	11(12)
Other	10 (11)

* Demographic data are missing for one participant.

Table 2.

Information about patient death and subsequent interviews with bereaved caregivers

	n (%)
Days between patient death and caregiver interview (mean +/- STD, range)	53 +/- 19, 28-133
Patient enrollment in hospice between starting VOICE study and death	
Yes	66 (73)
No	17 (19)
Unknown	8 (9)
How interview was conducted	
In person	53 (58)
Over the telephone	28 (31)
No data	10 (11)
Location of in-person interviews	
Home	25 (47)
Outpatient clinic	6 (11)
Other	22 (42)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3.

Quotations of caregivers jolted by awareness of dying

Becoming aware that patients would die sooner than expected
[Patient's fatigue and anorexia] were signs that my son and I would talk, that something wasn't right. But even then you, maybe like an ostrich, stick your head in the sand and think well, he'll come back. He'll come back around. (CG7, male other)
I knew he was sicker but I didn't think he was that sick. ... [Physician] actually gave me a heads up. I don't know how else to say it. A heads up that things could be, but you know, you just don't want it to be. ... We went from palliative care to hospice care to dying within almost twenty-four hours. ... I just never expected it, never. (CG98, wife)
[Patient] did so well for so long that, oh, I don't know whether it's denial. I don't think it's denial but you think it can go on forever. ... I thought all this week here he was dying and we didn't talk about it. ... You think this is not happening, that type of thing. (CG66, wife)
Feeling inadequately informed that patients were dying
Would [Patient] probably have died quicker? Probably. Who knows. But the point is, is that even if it's three weeks of good quality it's better than six months of none. Basically what my sister did was fight to die. That's what she did. From misinformation. ... The way [the oncologists] present their treatment, it's more like yeah, wow, here we got a case, let's do this. Well, let's take the patient into consideration. That's my take on that. ... [We were] left to believe that yes, this is going to work; oh, sorry, it didn't. (CG70, sister)
I just wish they could have maybe delved more into the real side effects of the chemo, that maybe you might give it second thoughts and decide against it. But when you come in, you are putting yourself in their hands. ... [Patient] asked right out, you know, well how much more time? [The oncologist] said well, we can't really tell you how much more time. It might give you another six months, you know. And I don't think it was worth that. So in that regard I wish they would have just told us how devastating the chemo could be. (CG124, brother)
I think when [Patient's husband] found out she was that bad, it really was a shock to him and he, it's almost like he was panicking because he even wrote her a letter saying you've got to fight this, [Patient], I need you. You know, almost like a desperate thing like this can't happen. It was horrible. It was just so sad that he knew that he wasn't ready for this. (CG93, sister)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 4.

Quotations of caregivers caught in the middle of decisions pitting what patient want against what caregivers think is best

<p>Coaxing patients to change their minds about palliative care/hospice</p> <p>[Opting for palliative care] was probably for the best. I didn't want [Patient] to suffer but then I have second thoughts. (CG90, husband)</p> <p>[Patient] just couldn't be alone at night any longer and [going to a comfort care home] was the only way that we could provide her with twenty-four hour care. And I'm not sure that – she fought us to the very end about going to the comfort care home. – We wanted it so much to be her decision to go. We didn't want to have to make that decision for her. (CG45, female other)</p>
<p>Deciding whether to do more or less than patients had wanted</p> <p>[Patient] was also very much a fighter. ... I had hope that he would have twenty-four hours' worth of antibiotics because nobody knew where the infection was coming from. [Physician] did not know at that time that his stomach had been destroyed. I mean, if we had known that at that time, I would have said no, just don't do anything. (CG115, wife)</p> <p>We could have said no, we don't want to do that and [instead] get [Patient] as strong as you can and I'm gonna pack her up in a wheelchair and take her home. And sometimes I say to myself maybe I should have told them that. But I don't know how much longer she would have lasted. And I'm sure the quality of life was going to keep deteriorating. I mean the best analogy of it all ... is if you've ever had a dog that you love or a pet and they finally reach an old age state where their health is totally shot and they're very miserable and they're just laying around, they are barely breathing and you are still trying to keep them alive, then you have to ask yourself am I keeping them alive for them or am I just being selfish and I don't want to lose them so I'm gonna just keep them here to keep them here. ... There's a point where you have to say, like I told her, I didn't want her to suffer. (CG90, husband)</p>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 5.

Quotations of caregivers finding gratitude, peace, and purpose

<p>But other than that I'm very blessed, I'm very fortunate I was able to be with her as much as I was, to take care of her in ways that I never thought I would my sister. ... I was never frustrated with doing it. It was an honor to do. And if I knew the outcome would be the same, if you had that chance they say in life would you do it again, yes, I would. If I knew I would get the same outcome again I would do it. (CG70, sister)</p>
<p>And [Patient] took this deep breath and just let it out. And it struck me how beautiful she was in death, you know, with no pain, no stress. She was prettier, more beautiful than I'd seen her in a long time, months. ... It was really an amazing and a beautiful moment but a terrifying experience. (CG17, husband)</p>
<p>I said well, I don't need anybody in the home, I can take care of [Patient]. I wanted to make sure she stayed here. That's what she wanted. (CG188, husband)</p>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript