



Published in final edited form as:

*Support Care Cancer*. 2019 February ; 27(2): 669–675. doi:10.1007/s00520-018-4365-0.

## Family Caregiver Descriptions of Stopping Chemotherapy and End-of-Life Transitions

Norton SA<sup>1,2</sup>, Wittink MN<sup>3,4</sup>, Duberstein PR<sup>2,3,4</sup>, Prigerson HG<sup>5</sup>, Stanek S<sup>1</sup>, and Epstein RM<sup>2,3,4,6</sup>

<sup>1</sup>School of Nursing, University of Rochester

<sup>2</sup>Department of Medicine, Division of Palliative Care, University of Rochester

<sup>3</sup>Department of Family Medicine, University of Rochester

<sup>4</sup>Department of Psychiatry, University of Rochester

<sup>5</sup>Department of Medicine, Weill Cornell Medicine

<sup>6</sup>Wilmot Cancer Center, University of Rochester

### Abstract

**Purpose:** The purpose of this study was to describe family caregivers' perspectives of the final month of life of patients with advanced cancer, particularly whether and how chemotherapy was discontinued and the effect of clinical decision-making on family caregivers' perceptions of the patient's experience of care at the end of life (EOL).

**Methods:** Qualitative descriptive design using semi-structured interviews collected from 92 family caregivers of patients with end stage cancer enrolled in a randomized clinical trial. We used a phased approach to data analysis including open coding, focused coding, and within and across analyses.

**Results:** We identified three patterns of transitions characterizing the shift away from active cancer treatment: 1) "*We Pretty Much Knew*," characterized by explicit discussions about EOL care, seemingly shared understanding about prognosis and seamless transitions from disease-oriented treatment to comfort-oriented care, 2) "*Beating the Odds*," characterized by explicit discussions about disease-directed treatment and EOL care options, but no shared understanding about prognosis and often chaotic transitions to EOL care, and 3) "*Left to Die*," characterized by no recall of EOL discussions with transitions to EOL occurring in crisis.

**Conclusions:** As communication and palliative care interventions continue to develop to improve care for patients with advanced cancer, it is imperative that we take into account the

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Corresponding Author: Sally A. Norton, Sally\_Norton@urmc.rochester.edu (ph 585-275-9814).

Conflict of interest:

The authors declare no conflicts of interest.

Data Access:

Primary data for this study are held with the principal investigators (PD and RE) named. Based on our Institutional Research Subjects Review Board approval, these data cannot be made openly available for ethical reasons—qualitative interview transcripts describe the personal and specific contextual experiences of subjects who might be identifiable in the data. Requests for de-identified data will be considered on a case-by-case basis.

different patterns of transition and their unique patient and caregiver needs near the end of life. Our findings reveal considerable, and potentially unwarranted, variation in transitions from active treatment to death.

### Keywords

Cancer; Caregiver; Communication; Decision Making; End of Life; Palliative Care; Prognosis

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### Background

Most patients with advanced cancer and their families report a desire for information about their clinical condition and to be involved in decisions regarding their care at the end of life (EOL) [1–3]. Prior reports support that patients who had discussions about the type of care they wanted at the EOL were less likely to receive aggressive disease-directed treatments and more likely to enroll in hospice [4]. Yet, these discussions often do not happen, and even when they do, patients and clinicians often report different understandings of the disease, treatment options and prognosis [5]. Perhaps as a consequence of these different understandings, too commonly patients with advanced cancer receive aggressive life-prolonging treatments that diminish quality of life for patients (and possibly caregivers) with nominal impact on survival [6–9].

Patients with incurable cancer engaged in active cancer treatment, their caregivers, and clinicians face complex choices. Discussions about the possibility of stopping disease-directed treatment, when they happen, are made in the context of looming death and influenced by the patient's worsening condition, emotions, family involvement and interactions with clinicians [10]. Family caregivers play an important role in providing physical and emotional care and support to patients with advanced cancer, especially as a patient's condition worsens [11]. They traverse the health care system with patients, are often present when oncologists share prognostic information [12, 13], and frequently serve as the providers of care during patients' last weeks of life [14]. Caregivers' perspectives thus provide an important window into the relationship between conversations and decisions about stopping chemotherapy and patients' experiences in the last weeks of life.

The purpose of this paper is to describe family caregivers' perspectives of the final month of life of patients with advanced cancer, particularly whether and how chemotherapy was discontinued and the effect of clinical decision-making on caregivers' perceptions of the patient's experience of care at the end of life.

### Methods

Data used in this qualitative descriptive study are part of the Values and Options in Cancer Care (VOICE) study. The VOICE study was a multi-center cluster randomized trial of an intervention to improve oncologist-patient-caregiver communication in the context of advanced cancer [15, 16]. Institutional review board approval was received and informed consent was obtained from all participants in the study. As part of the original research design, we prospectively identified and enrolled caregivers who patients identified as a family member, partner, friend or someone else involved in their health care [16]. Using a

semi-structured qualitative interview guide we explored caregivers' experiences and perceptions of treatment decision-making, patients' transitions out of active cancer treatments, and patients' experiences of care during their last month of life.

Among the patients who died, 125 had caregivers enrolled in the study, 98 of whom participated in the semi-structured interviews. The remaining caregivers were lost to follow-up (19), withdrew (4), or were unable to be scheduled within the follow-up time frame (4). We consecutively sampled interviews and conducted analyses until data saturation [17] was achieved leaving a final sample size of 92 caregivers (see Table 1).

Interviews lasting between 15–45 minutes were conducted in-person (58%), over the telephone (31%), or not indicated (11%), on average of 52.9 days (SD 19.3 days) following the patient's death. Interviewers were well-known to participants based on their participation in the clinical trial. All interviews were audio-recorded, transcribed, de-identified, verified and entered into Atlas.ti 7.1 for data management [18].

We used a 3-phased coding approach for data analysis allowing for both pre-specified (prior to data collection) and emergent domains (identified during data analysis) [17]. Prespecified domains included study enrollment arm, decision-making, experience as caregiver, and hospice enrollment. During phase 1, we conducted open coding, a process of identifying and labeling ideas in the text [19]. We then coded the pre-specified domains, compared those results with the open coding, and thereby identified emergent domains. We developed a coding scheme reflecting both pre-specified and emergent domains. Emergent domains included system gaps/experiences, unacknowledged decision points, and recognition of imminent death. During phase 2 all transcripts were coded, analyzed, and compared across intervention and control groups. No discernable differences were identified. However, across both groups we noticed dramatic variations in caregiver reports of transitions and gaps in care near the EOL and thus made a methodological decision to focus our subsequent analyses around this emergent domain. During phase 3 we grouped our narratives based on transitions and gaps near the EOL, and examined within and across those groups for patterns in decision making, cancer treatment cessation and hospice enrollment. To strengthen the validity and trustworthiness of our findings we used negative case analyses and an audit trail [20].

## Results

We identified three patterns of transitions characterizing the shift away from active cancer treatment: 1) "*We Pretty Much Knew*," Connected Transitions, 2) "*Beating the Odds*," Chaotic Transitions, and 3) "*Left to Die*," Crisis Transitions.

### **"We Pretty Much Knew," Connected Transitions**

This pattern was characterized by explicit discussions about EOL care, clear decisions, and seamless transitions from active cancer treatment to comfort-oriented care, usually hospice. Decisions were the product of shared understanding between patients, caregivers, and their oncology team that further cancer treatment would result in more harms than benefits and that hospice would afford patients care that was concordant with their values.

Caregivers gave detailed descriptions of these discussions. Oncologists would use medical data (e.g., imaging or laboratory tests) to suggest that disease-oriented treatment was no longer feasible, while patients and caregivers drew similar conclusions from their experience with symptoms such as fatigue, lack of appetite, and poor recovery between chemotherapy doses. Often, from the caregivers' perspective, *the patient's body* had made the decision; the body could no longer tolerate chemotherapy. "*They just couldn't get a full cycle of chemo in her... her body couldn't take it, couldn't bounce back. So there was no reason to continue treatment.* [cg64]

Caregivers described that physicians', caregivers' and patients' different perspectives all pointed to similar conclusions that further chemotherapy was not warranted. In reaching this shared understanding, the physician's suggestion to stop chemotherapy did not surprise patients or caregivers; it was the obvious and sensible (albeit unwelcome) next step.

He [husband] went in for his final scan [then] we went in and saw Dr. [oncologist] and he was very compassionate and very kind and very forthright and said, 'the tumors are worse and there's no more point to chemo. All its doing is making you sick with no positive benefit.' That is when he said, 'I'm going to stop chemo and going to recommend that you go into hospice.' And I was not surprised. I had been watching [husband] decline.

[cg63]

In this case, the oncologist prepared the patient and his family by having "*been clear all along from day one. He said chemo will buy you time. It's not going to cure anything,*" [cg63] paving the way to a shared decision to pursue hospice care.

For a few patients, caregivers described the move to hospice triggered solely by the patient. As the wife of one patient described: "*he [husband] said 'I've had it, that's it, I'm done.' He said, 'get those pills, throw them out. All they are doing is making me sick.'*" [cg24] The patient stopped chemotherapy, spent his last month of life in hospice, and passed peacefully.

In sum, caregivers of patients in the connected pattern were much more likely than others to offer positive memories around life closure, including that patients' wishes were discussed and enacted. These caregivers noted that the transitions were emotionally difficult, yet they were able to have open discussions about preferences for EOL care, had shared understanding with their clinicians and were able to anticipate their needs in the last few weeks of the patient's life.

### **"Beating the Odds," Chaotic Transitions**

This pattern was characterized by explicit discussions between patient, caregiver and oncologist about disease-directed and comfort-oriented treatment options, as with *Connected Transitions*, but there was not a shared understanding about prognosis and treatment choices. Two disconnects between perspectives of patients, caregivers and oncologists were apparent. First, despite data on limited effectiveness, patients requested chemotherapy until all offered cancer treatments were exhausted. Second, while caregivers (and patients) were aware that the cancer was incurable and would likely result in the patient's death, they believed that the patient would die in the distant future and seemed unaware of the nearness of death.

Transitions to comfort-oriented care were typically chaotic and within days of death, if they occurred at all.

Caregivers described how the lack of shared perspective manifested in clinical encounters. Patients and caregivers usually agreed with the clinician on particular clinical facts about the patient's condition; however, they interpreted those facts differently. Caregivers often described that the patient was unique in a way which justified continuing active cancer treatments, perhaps that the patient was a "fighter" or someone who never gave up despite the odds. They considered such patient characteristics more important than clinical data in their decision making. Often caregivers reported more than one discussion about stopping disease-directed treatment, but each time the patient made a deliberate choice to continue. One caregiver explained: "*He felt optimistic. He thought he was essentially beating the odds up until close to the end.*" [cg19] Her husband was hospitalized a couple of times during his last month of life and died in the hospital. Another caregiver reported how her husband opted for third-line chemotherapy:

[The patient] had been in two different kinds of chemo treatments and the last CAT scans showed that the chemo had not done its work. So they said that he had three choices: try another chemo treatment, discontinue treatment, or try experimental. And he, without even hesitating, said I'm gonna try the new chemo because even though it's only 5% chance, a 5% chance is better than none.

[cg10]

She continued: *It was important for him to always try. He was such a fighter that he just wanted to do something.*" She was appreciative that his oncologist respected the patient's decision despite the oncologist recommendation to stop chemotherapy.

I really think Dr. [oncologist] was encouraging him not to have the treatment. But the minute he saw that [the patient] was leaning that way he was very understanding. I could see him just kind of switch and respect exactly what [the patient] wanted.

[cg10]

This patient stopped active cancer treatment only when he was told that there were no other cancer treatments available.

Most of the patients in this group transitioned to comfort-oriented care when their condition deteriorated rapidly, usually within days of death; many caregivers reported having been overwhelmed by the news that further cancer treatment was not feasible and had not planned for this eventuality. One caregiver described how he couldn't bring his wife in for her chemotherapy treatment because she was too ill:

She kept getting sicker and sicker and not eating. I knew things were getting bad. We knew she was getting worse. And I said I don't know what to do. Then Monday I called [hospice] and they came right out. She basically hung on through Thursday and then the next morning passed away.

[cg22]

While caregivers in this group described difficulties in supporting and caring for the patient, they also acknowledged that the patient had been provided information and made his/her own choices. While caregivers reported receiving information from the patient's oncologist about cancer treatments, and their relative effectiveness, they felt unprepared for rapid deteriorations in the patient's condition and described that their oncologists were not as responsive at those times as they would have liked. They knew that the patient was going to die but also reported being taken by surprise when their loved one experienced a rapid decline toward death; their last days with the patient were usually chaotic, with rushed changes in the patient's plan and location of care even when hospice was ultimately involved.

### **“Left to Die,” Crisis Transitions**

No recall of explicit EOL discussions with their oncologists characterized this pattern. Caregivers often were told by emergency department or ICU personnel that the patient was dying (not their oncologist), and frequently described high levels of distress and feeling abandoned by their oncology team. Caregivers described a very difficult dying process: an unanticipated decline in the patient's condition, a lack of clarity regarding which health care provider they should call, a sense of abandonment by and anger at the oncology team, emergency hospitalizations, and a lack of recognition that the patient's deteriorating condition indicated imminent death. Chemotherapy for these patients was almost always discontinued only when the patient became too sick and/or experienced a health crisis. In one example, the caregiver described a series of escalating adverse health events requiring hospitalizations and ICU admissions, yet their interpretation of the oncologist's communication reinforced their hope that the patient's condition would improve sufficiently to resume chemotherapy, but ultimately they felt abandoned:

[H]er oncologist, was like ‘there is no way we can do chemotherapy at this time. We need to kind of build her strength back up.’ Anyway, that just did not happen. Things started going downhill rapidly. I had to take her into the hospital; she was in the ICU for a couple of days. And then they moved her out of the ICU the last day. But [the ICU physician] told us she was dying. I could not get [her oncologist] to call. He didn't even return the calls to the ICU doctor. So I was pretty angry.

[cg86]

Caregivers did not recall discussions about prognosis or times when a possible transition to comfort-oriented care was discussed. As one caregiver said:

The only thing that was said to us was after we went through the two rounds of chemo was that he was stable. But I mean in terms of here's the options, you might not want to do this again because look at you now, that was never talked about...it was more of a, ‘this is what we're gonna do.’ ... It wasn't being communicated that you're not doing well. You know, so maybe you might want to just lay up on the chemo and let you enjoy your life. There was never that option there. It was like come back in 3 weeks.

[cg59]

Several caregivers reported having reached out to the patient's oncologist during a crisis only to be referred to the emergency room and then jarred by messages from clinicians in the emergency department or hospital that contradicted the oncologist's hopeful stance.

We were hearing from the oncologists – there was so much hope. She [the patient] goes to the emergency room and this doctor just basically said 'you're gonna die.' And the [ER] doctor also said 'oncologists generally won't admit that.'

[cg39]

Caregivers' assumptions about patients' illness trajectories were abruptly and alarmingly disrupted, and they reported feeling frustrated, angry, and deceived because no one had helped them anticipate the terminal decline. Most often their anger was directed toward oncologists. A few caregivers noted that they had been excluded from patient-oncologist conversations and the patient may have chosen not to inform them about any EOL conversation that might have occurred.

Caregivers also described a disturbing liminal state between active cancer treatment and hospice, one in which they felt abandoned:

It's just a bizarre, weird in-between time where you feel like, like you are just left to die. I felt like my mom was just left to die.

[cg36]

It just seemed like they [the oncologists] wrote her off. ... It just seems like she was written off and that was it. ... It was just, 'well that's it, we've got other things to do.'

[cg55]

Mistrust, deception, and betrayal were common themes: "*I know they [oncologist] knew more [about] how bad she was than they actually told us.*" [cg94] Consequences of a lack of shared understanding could be particularly traumatic:

Well, she didn't want anything as far as life-saving, tubes. But when I brought her to the Emergency Room the second time, all of a sudden she just said she couldn't breathe. And I screamed for the doctors. And they put a tube in her, you know, to breathe. And that was against her wishes. Now that's not their fault. I was so upset at that time. I basically gave them permission.

[cg92]

After two days on a ventilator in the ICU, his wife was extubated and died.

In summary, caregivers in the *Crisis Transition* pattern reported having experienced trauma, distress, anxiety, panic, uncertainty, and self-blame and felt angry, frustrated, deceived and abandoned by the oncology team for providing insufficient information and no guidance. Their decisions about life-sustaining treatments were made hastily in the emergency room and in the ICU without the involvement of physicians whom they had known.

## Discussion

Twenty years of research in end-of-life communication supports associations between prognosis discussions and generally better patient outcomes, including symptoms, quality of life, and health care utilization. However, findings are not always consistent [4, 21–23] and there is a fair amount of heterogeneity that warrants qualitative exploration. Our findings from analyses of caregivers' perspectives complement a prior description of decisions to stop chemotherapy based on physician notes or lack thereof [5]. Two of the patterns identified by Pirl and colleagues, definitive decision and no decisions, complement *we pretty much knew* and *left to die* respectively. Our pattern, *beating the odds*, also has similarities with the deferred and disrupted decisions described by Pirl. Our study provides additional depth and context by identifying distinct patterns from the caregiver perspective of patient-caregiver-physician communication that influence the transition from disease-oriented to comfort-oriented care that appear to affect the experiences of caregivers and patients in the patient's final days.

Of the three patterns identified, that which was associated with the least caregiver distress and greater satisfaction with care had two key characteristics: open communication about the intent and likely outcome of treatment as well as three components of shared mind in the context of medical decisions—shared understanding, shared deliberation, and shared decisions [24]. Although the extent to which shared mind is a consequence of open communication or a product of other relationship attributes is unknown, open communication set the stage for smooth transitions to comfort-oriented care.

Caregivers of patients who recalled explicit conversations with clinicians about the patient's poor prognosis, regardless of their decisions about treatment, described that their choices were honored. In contrast, patients and caregivers suffered to a greater degree when they only had information about the disease but lacked shared understanding of prognosis, when deliberations were ineffective, and when decisions did not reflect a shared perspective among physicians, patients, and caregivers. Caregivers reported not having had information which allowed them to anticipate, identify, and respond to rapid deteriorations in patients' conditions. While patients and their caregivers reported having been informed of the limitations of available treatments, and elected disease treatments without clear benefit, they also seemed 'blindsided' by the nearness of death and what an imminently dying patient might look like. In cases when patients were trying chemotherapy despite the odds, or taking a 'temporary' chemotherapy vacation, communication about the nearness of the patients' death, no matter what was actually said, seemed not to have occurred. Consequently, caregivers and patients were surprised when the patient's condition deteriorated rapidly. Guidance and clear plans about what to expect during the terminal phase of illness would have been helpful but were not forthcoming.

Finally, those who recalled no conversations at all seemed to suffer the most. They described discontinuities in care and confusion about what to do when the patient's condition worsened. When caregivers were unprepared, their anxiety sometimes led to more life-sustaining treatments than patients had wanted and to greater self-blame, guilt and regret. There was a breakdown of trust; caregivers felt abandoned, deceived, and angry. Oncologists



may have had the patient's best interests at heart but from caregivers' perspectives, they had not fulfilled their obligation to be there when patients needed them the most [25].

Our findings identified 2 groups of patients with advanced cancer in need of additional supports, patients who wanted to continue active treatment of questionable benefit and those for whom chemotherapy was stopped or paused because they were too ill. While our study is descriptive, we surmise that both groups would have benefited from a standardized protocol that 1) was automatically triggered by belonging in one of the two high risk groups, 2) provided information on identifiable signs and symptoms that might indicate the patient's condition is deteriorating, 3) offered routine monitoring telephone calls, and 4) developed an emergency plan which included an emergency contact telephone number with their oncology team and/or identified clinician such as their primary care provider who could rapidly respond to changes in the patient's condition. How systems might respond to urgent calls would depend on the unique contextual features of the cancer center. Larger practices may have the capacity to develop a rapid response team whereas smaller centers may lean more toward liaisons with community clinicians.

Our study is limited by having elicited only the caregiver's perspective. Caregiver recall may have been influenced by the outcomes; difficult deaths may have prompted selective recall of more negative experiences. We cannot know which discussions did not occur and which occurred but were forgotten. Moreover, caregivers may not have been privy to all the discussions between oncologists and patients.

## Conclusions

These findings point the way to more effective conversations between clinicians and patient regarding EOL choices for patients with advanced cancer. Our findings reveal considerable, and potentially unwarranted, variation in caregiver experiences of transitions from active treatment to death. By identifying in greater detail qualities of effective and ineffective management of emotionally-charged situations in which the stakes are high and providing clear signposts for patients and caregivers with terminal illness on how to recognize terminal decline we can hope that clinician training might allow them to avoid actions that lead to patients and caregivers feeling abandoned. Findings also provide direction for health care systems to better coordinate care during transitions and clinically expected declines among patients with advanced cancer. The importance of clear planning and anticipatory guidance for this group cannot be overstated.

## Acknowledgments:

This study was funded by grants received from the National Institutes of Health, National Cancer Institute: R01CA1404191 and R01CA168387

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**Table 1**

## Caregiver Demographics

	N	%
<b>ALL AGE</b>	<b>91*</b>	<b>100</b>
	<b>Mean 64 SD 12.1 Range 23–84</b>	
<b>Race</b>		
Non-white	12	13
White	79	87
<b>Gender</b>		
Female	61	67
Male	30	33
<b>Education</b>		
HS or less	23	25
Some college or more	68	75
<b>Marital Status</b>		
Committed/Married	72	79
Divorced/S eparated	7	8
Widowed	4	4
Never married	8	9
<b>Income</b>		
\$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
<b>Relationship to Patient</b>		
Committed/Married	59	65
Adult Child	13	14
Other	19	21

\* demographic data missing for 1 subject