

PAPER

Patients' and oncologists' views on family involvement in goals of care conversations

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Abstract

Objective: Family members can significantly impact advanced cancer patients' treatment and are important participants in goals of care (GoC) conversations. Yet, research on patient and physician perspectives about family involvement and influence on GoC conversations is limited. Our purpose was to describe patients' and oncologists' perspectives about family involvement and influence on GoC conversations among patients with advanced cancer.

Methods: We conducted semi-structured interviews at academic, community, and municipal hospitals ($n = 4$) with patients with advanced cancer ($n = 39$) and their oncologists ($n = 21$). Interviews were audiotaped and transcribed. We analyzed data using interpretive description. Three coders independently coded transcripts, compared codes, and resolved discrepancies.

Results: We identified 4 themes common to patients and oncologists regarding family involvement in GoC conversations: (1) Presence and Duration of Family Involvement; (2) Family Expectations; (3) Protecting patients'/Family Members' Feelings; and (4) Patient-Family Disagreement. For patients, we identified 2 additional themes: (1) Family and Oncologist Relationship and (2) Effects of Cancer on Family. Both patients and oncologists emphasized the importance of family support for the patient's understanding of their illness and on patients' emotions. We also identified ways in which family involvement may benefit or prove challenging to GoC conversations.

Conclusions: Patients and oncologists have similar views about family involvement in GoC conversations. Learning how to communicate with family members should be a critical component of physician education in palliative care.

KEYWORDS

cancer, oncology, goals of care conversation, family involvement, oncologist communication, qualitative research

1 | BACKGROUND

Goals of care (GoC) conversations are discussions about prognosis, treatment options, treatment risks and benefits, and care planning. These conversations help clarify patients' values to guide the intensity of care. In patients with advanced cancer, these conversations are critical to help direct care, yet less than 40% of advanced cancer patients have GoC conversations, and often these conversations happen late in the disease course.^{1,2}

Family involvement can significantly impact advanced cancer patients' treatment and GoC conversations by influencing patients'

decision-making or impacting patients' ability to cope.³⁻⁷ Hobbs et al found that most cancer patients involve family in decision-making but that non-English speaking patients relied more heavily on family.³ Laidsaar-Powell and colleagues showed that families can play multiple roles by asking about treatment options, prompting questions, or providing information.⁴ However, there is considerable variation in the degree of family involvement in treatment decision-making.⁸ Few researchers have compared patient and physician perspectives on family involvement in GoC conversations and their influence among patients with advanced cancer. Our purpose was to describe patients' and oncologists' perspectives on family

involvement and influence on GoC conversations among patients with advanced cancer.

2 | METHODS

In this qualitative interview study, we purposively sampled patients with advanced cancer and attending oncologists from 4 hospitals and community clinics in New York and Connecticut. The study sites represented academic, community, municipal, and rural settings. Although some of the participating oncologists were treating participating patients, interviews were conducted independently (ie, they were not dyadic interviews). Experienced interviewers (NB, SF, DSG, JL, CS) conducted all interviews, which were recorded and transcribed. This study was approved by the Institutional Review Boards of all participating institutions.

2.1 | Sample and procedures

2.1.1 | Patients

Eligible patients were adults aged ≥ 21 with a pathologically confirmed diagnosis of advanced cancer who had received at least first-line treatment and who spoke English. We identified eligible participants through oncologists at participating study sites and contacted them via a letter from their oncologist. A research assistant approached potential participants at their oncologist's visit, discuss the study, and determine patients' interest in participating. Research assistants requested written consent from interested patients and collected basic demographic and clinical information. Interviews took place in a private setting at the patients' referring hospital, clinic or home. Patients were excluded if they were cognitively impaired as determined by the referring oncologist or interviewing physician.

We began the semi-structured interviews by presenting a hypothetical case of a patient with advanced cancer to initiate discussion about GoC conversations in a less personal manner to help ease patients into this potentially sensitive topic. We followed with questions about patients' preferences for GoC conversations, including if and/or how family should be involved in these conversations. These questions included, "With whom do you think the patient should discuss [GoC] issues? (Probe: oncologist, family caregiver?)" and "Who should initiate the goals of care conversation? (Probe: patient, oncologist, family caregiver?)." We continued interviewing until we achieved theme saturation.

2.1.2 | Oncologists

Eligible oncologists were solid tumor attending oncologists at one of the participating study sites who saw at least 2 new advanced cancer patients per month. We asked interested participants for written consent and collected basic demographic and practice information. We also asked oncologists to complete a brief survey on their communication skills training and comfort conducting GoC conversations. Interviews took place in a private setting at the oncologists' respective study sites.

Interviews were semi-structured and designed to take approximately 30 minutes. Questions tapped into what GoC conversations

usually "look like," as well as facilitators and barriers to these conversations, among other topics.

2.2 | Data analysis

We used interpretive description as an approach to data analysis. Interpretive description employs principles for analytic frameworks, sample selection, data analysis, and rigor to conduct inquiries into human health and illness experiences.⁹ We assigned separate coding teams for patients (DSG, JL, CS) and oncologists (SF, DSG, JL, CS). Each coding team began by reading transcripts line-by-line for accuracy while listening to the corresponding audiotape. Coders coded data with descriptive phrases to capture key concepts. Once coders completed this process for the first 3 transcripts in their data set, coders created an initial code key for their data set. Coders expanded and refined their code keys through independent and then joint review of subsequent transcripts. Coders compared and discussed codes until they reached agreement. We applied the final code key for each data set to each set of transcripts.

We used the Atlas.ti (Scientific Software, Berlin, Germany, version 5.0) to produce code reports. Coders triangulated findings from each data set to compare and contrast patient and oncologist data for areas of consistency, complementarity, and divergence. Specifically, we examined patients' and oncologists' reports regarding family involvement in GoC conversations, assessed how commonly family involvement was described from each perspective to identify themes within and across groups, and discussed why 1 group did not identify a theme that was reported by the other group. Coders documented ideas and questions throughout the analytic process and periodically discussed findings with all team members, including oncologists, patient stakeholders, and representatives of cancer advocacy organizations. This iterative and inclusive approach enabled us to refine interview questions, to ensure that we reached theme saturation, and to explore emergent themes within and between oncologist and patient datasets.

3 | RESULTS

3.1 | Patient sample ($n = 39$)

Interviews with patients lasted an average of 34 minutes (range 24–58). Patients had a mean age of 58 years (range 26–88) and most (59%) were female. Forty-one percent were White, 38% were African American, 3% were Asian, 15% reported their race as "Other," and 3% did not report their race. Participants had various cancer diagnoses, including lung ($n = 9$), breast ($n = 7$), colon ($n = 7$), pancreatic ($n = 4$), prostate ($n = 3$), and one each of renal cell, thymoma, appendiceal, biliary, esophageal, gastric, head and neck, and tongue cancer and glioblastoma.

3.2 | Oncologist sample ($n = 21$)

Interviews with oncologists lasted an average of 34 minutes (range 15–48). Oncologists had a mean age of 46 years (range 34–68), and most (67%) were male. Seventy-one percent were White, 24% were

Asian, 10% were Hispanic, and 5% were Black. Oncologists reported an average of 20 years in practice (range 8–42), and 52% had received training on having GoC conversations.

Descriptions of both groups appear in Table 1.

3.3 | Themes

For patients and oncologists, we identified the following themes related to family involvement in GoC conversations: (1) Presence and Duration of Family Involvement; (2) Family Expectations; (3) Protecting Patients'/Family Members' Feelings; and (4) Patient-Family Disagreement. Two other themes, (5) Family and Oncologist Relationship and (6) Effects of Cancer on Family, were identified only by patients (Table 2). We discuss similarities and differences between patients' and oncologists' views for each theme below.

1) Presence and Duration of Family Involvement

3.4 | Presence of family

Both patients and oncologists recognized the importance of family involvement in patients' lives and in GoC conversations. Patients felt that family should be involved in GoC conversations because the illness affects not just the patient but also the family. A patient stated "I noticed in my situation that I ain't going through it, but my family is going through it, too."

Oncologists highlighted that families could participate in GoC conversations by helping to clarify patient information, such as medical

history, functional status at home, and other sources of support. An oncologist summarized:

I think it's vital that the family, if the patient so wishes, is involved because it will help. It will help in the care. It will help in the meeting ground of what I'm really saying or what we're really saying or what the patient is really saying and maybe I'm not understanding. [Families are] almost like an interpreter of what's happening at home... Sort of a bridge. Or I find that the family members also share much more. "He's really not eating, pain is not really controlled, he's not really sleeping."

Oncologists also felt that family involvement could empower patients to take an active role in their care. Both patients and oncologists recognized that family involvement was crucial to help with making treatment decisions if patients did not want to take an active role in GoC conversations. For example, a patient reported, "In the beginning, it was, 'Don't tell me anything. Tell my family', because what am I going to ask? I don't know what this is all about." An oncologist echoed this:

If a patient stops me, I ask them why, and ask them how far they want me to go in terms of the details of what they want to know... [or] if [they] want me to defer those discussions to the other family members... then this person is going to kind of filter the information and give it to the patient.

Thus, patients and oncologists felt that families could help by acting as an advocate for the patient, by asking questions on behalf of the patient, and by serving as the decision-maker if the patient is unable to or does not want to make health decisions. The 1 challenge that oncologists reported was that it could be difficult to determine which family members should get what information because some may want more or less detail about the patient's diagnosis, prognosis, and treatment.

3.5 | Duration of family involvement

Patients and oncologists differed regarding the duration of family involvement over the course of the patient's illness. While both agreed that family should be involved at diagnosis, patients varied in the degree to which they felt family should be involved over time. A patient stated, "Sometimes you don't want to have your family to know. In the beginning, I think someone should be there... but as far as... being constantly told about what's going on, it's better if [only] I know." Thus, while many patients wanted ongoing family support, some preferred that family were not consistently involved over the course of treatment.

By contrast, oncologists preferred that family stay involved throughout the course of treatment so that information did not need to be repeated. Oncologists reported that it could be time-consuming to have multiple conversations with different family members, both during office visits and outside of the visit. One oncologist stated, "Sometimes you have family members suddenly come in. They're children or other relatives that weren't so involved... It's very hard."

TABLE 1 Characteristics of oncologist and patient samples

Characteristic	Oncologists (n = 21)	Patients (n = 39)
Mean age (range)	46 (34–68)	58 (26–88)
Years in practice (range)	20 (8–42)	--
Training in goals of care conversations, N (%)	11 (62)	--
Gender, N (%)		
Male	14 (67)	16 (41)
Female	7 (33)	23 (59)
Race, N (%)		
White	15 (71)	16 (41)
Asian	5 (24)	1 (3)
Black	1 (5)	15 (38)
Other	--	6 (15)
Unknown	--	1 (3)
Ethnicity, N (%)		
Non-Hispanic	19 (90)	--
Hispanic	2 (10)	--
Cancer type, N (%)		
Lung	--	9 (23)
Breast	--	7 (18)
Colon	--	7 (18)
Pancreatic	--	4 (10)
Prostate	--	3 (8)
Other ^a	--	9 (23)

^aIncludes renal cell, thymoma, appendiceal, biliary, esophageal, gastric, head and neck, tongue cancer, and glioblastoma (n = 1 each).

TABLE 2 Themes of goals of care conversations reported by patients and oncologists

Theme	Description of Theme	Benefits	Challenges
Presence and duration of family involvement (MD/PT)	Family participation in GoC conversations with or in lieu of patient involvement; family involvement over the course of the patient's illness	<ul style="list-style-type: none"> Acting as advocate for patient or decision-maker if patient is unable to or does not want to make decisions (MD/PT) Clarifying patient history or information (MD) 	<ul style="list-style-type: none"> Inconsistent or late involvement of family member(s) over time (MD) Time-consuming to have multiple conversations (MD)
Family expectations (MD/PT)	Family's understanding of and plan for the patient's illness	<ul style="list-style-type: none"> Sharing/ clarifying family values and congruency with patient values (MD/PT) Helping to achieve a common understanding (MD/PT) 	<ul style="list-style-type: none"> Family members may be in denial or not be able to accept/understand diagnosis or prognosis (MD/PT) Unrealistic expectations by family members about treatment (MD) Determining which family member gets what information (MD)
Protecting patients'/family members' feelings (MD/PT)	Recognition of the impact of patients' and families' emotions on each other and on GoC conversations		<ul style="list-style-type: none"> Managing multiple individuals' feelings and opinions (MD/PT) Understanding and managing family dynamics (MD/PT) Families don't want patient to know diagnosis (MD) Protecting family's feelings, not wanting family to know treatment details (PT)
Patient-family disagreement (MD/PT)	Disagreement about diagnosis or treatment between patient and family or among family members		<ul style="list-style-type: none"> Disagreement or dissent about diagnosis or treatment (MD/PT) Family members may pressure patients to continue treatment (MD/PT)
Family and physician relationships (PT)	Family members' relationship with patient's oncologist is important to patient	<ul style="list-style-type: none"> Good family relationship with physician increases patient trust (PT) 	
Effects of cancer on family (PT)	Patient's illness and treatment affect family members in multiple ways	<ul style="list-style-type: none"> Increases sharing of feelings with family (PT) 	<ul style="list-style-type: none"> Causes family to be overwhelmed to anxious (PT) Concerns about being a burden to family (PT)

MD/PT = reported by both oncologists and patients; MD = reported by oncologists only; PT = reported by patients only.

Inconsistent involvement of family over time or involvement of family late in the course of the patient's illness could make GoC conversations difficult. An oncologist noted:

If there is an inconsistency in the family members that help to take care of the patient it makes it really tough sometimes because sometimes the family members appear that I have never seen before and they are like why haven't you given this drug and this drug and I read about this drug and you have to, you know, cannot we put them on this... all sorts of things like that and then that just makes it much harder to have an effective goals of care discussion when there are people that haven't understood the process that suddenly appear and are interjecting all sorts of other stuff.

2) Family Expectations

Both patients and oncologists discussed the importance of consonance on patient-family expectations for cancer management and implications for the GoC plan. A patient expressed, "I think the family needs to be aware of what the patient's goals are and... how the patient is feeling about all of this." An oncologist echoed, "It is important to figure out if the patient and the family are not on the same page so that I can help to try to get them to be on the same page so that

they can actually have some meaningful communication." Thus, families can help facilitate GoC conversations by sharing and clarifying family values and by achieving congruency with patient values so that patients and families have a common understanding of the patient's disease and prognosis.

Both patients and oncologists reported that family members who were in denial or who were unable to accept or understand the diagnosis or prognosis could hinder GoC conversations. Oncologists pointed out that some family members may have unrealistic expectations about treatment efficacy or goals. One oncologist related:

I recently had a family meeting with one of [my] patient's three daughters. We were pretty much all on the same page that additional chemotherapy could harm more than help and that, given the patient's frailty, hospice made the most sense. He was on board with that. A couple of days later I got a call from two of his other daughters wanting to readdress this. They didn't understand why... and they were like, "I don't understand why my father cannot receive more treatment. I realize it's not curable but maybe we are talking about two or three years instead of one year." When the natural history of the disease is really six months or less without treatment.

3) Protecting Patients'/Family Members' Feelings

Both patients and oncologists recognized the impact of patients' and families' emotions on each other and on GoC conversations, particularly around diagnosis and prognosis. A patient described, "I'm calm if they're calm," while an oncologist reflected that "[patients'] emotional response... and what family members are there... sometimes how excitable they are, and things like that [can make GoC conversations difficult]."

Both groups discussed patients and families wanting to protect each other's feelings. While patients often talked about protecting family members' feelings, oncologists discussed families wanting to protect patients' feelings. A patient said:

Sometimes you do not want to have your family to know. Like I did not want my wife to know that [my treatment] is not working, and we would have to try something else, and I am already kind of discouraged, so I do not want them to feel as though I am going through this for nothing.

By contrast, oncologists discussed cases where families did not want the patient to know about the cancer diagnosis and some families who wanted oncologists to give patients cancer-directed treatment without having the patient know what was being treated. An oncologist reflected that "[family members] do not want [the patient] to necessarily know because they feel like the patient is going to get really anxious and depressed."

A challenge identified by both patients and oncologists about family involvement in GoC conversations revolved around how to manage multiple individuals' emotions and opinions. Additionally, both emphasized that managing family dynamics can be challenging in a GoC conversation, both from the patients' side who must manage their own family, as well as from the oncologists who must determine what the family dynamics are and how to manage them.

4) Patient-Family Disagreements

Disagreements between the patient and family or between family members acted as a barrier to GoC conversations. A patient stated, "Sometimes the people you think are going to be in your corner are not... my mother and I have had the biggest wars only since cancer. My mother is in total denial." An oncologist echoed:

The difficult family discussions are when there are a lot of different opinions and dissent among the participants of the family meeting, trying to arrive at a common understanding, especially trying to address questions that relate to, or coming from, someone who really has quite a bit of denial.

Patients and oncologists also commented that sometimes families may put pressure on patients to continue treatment, even when the patient may no longer be interested in cancer-directed treatment. A patient commented, "They mean the best and they want [the best] but they don't wanna let you go either... They keep it hanging on because they don't wanna lose [you], but to me that isn't right."

5) Family and Oncologist Relationship

Patients also discussed the importance of their families' relationship with their oncologist in facilitating GoC conversations. They emphasized that when oncologists have a good relationship with their family it helps to increase their trust and comfort. A patient stated that her husband's relationship with her oncologist "makes a world of difference in what I trust and what I don't trust." Patients reported that facilitators of establishing a good relationship between family members and oncologists included feeling that their oncologists were accessible, open-minded, took time to speak with their family, were able to speak to family members at different levels depending on family members' clinical knowledge, were willing to speaking with multiple family members, and were able to handle emotions.

6) Effects of Cancer on Family

Patients also spoke about how cancer affected their families and how these effects may affect GoC conversations. One patient said "I think [the cancer] impacts the family more than it does the patient themselves. You know, I'm just along for the ride. They've got to deal with the consequences." Patients generally felt that their cancer had a negative effect, often causing families to be overwhelmed, anxious or scared; and many spoke about their concern of being a burden on their family because of needing extra help. However, some patients also reported that the cancer diagnosis and GoC conversations had a positive impact by helping them have open conversations and allowing them to express their feelings with their family.

4 | CONCLUSIONS

We found that patients and oncologists shared similar views about family involvement in GoC conversations. Both emphasized the importance of family support on patients' understanding of their illness and on their emotions. Two themes, Family and Oncologist Relationship and Effects of Cancer on Family, were present only in the patient interviews. These themes may be unique to patients because oncologists may not be as aware of how much patients are concerned about the impact of their illness on their family or of the importance of the relationship oncologists have with family on the oncologists' relationship with patients. We identified ways in which family involvement may benefit or prove challenging to GoC conversations. Our work adds to the literature by highlighting areas where family involvement may impact GoC conversations both positively and negatively, and in particular, areas in which patients and oncologists may differ, such as duration of family involvement over the illness trajectory.

Involvement of family in GoC conversations offers valuable opportunities to enhance patient care that must be balanced with the challenges that come with adding additional participants to these conversations. Several studies have shown that there are discrepancies between patient-family, patient-physician, and family-physician understanding about cancer stage and treatment goals in advanced cancer,¹⁰⁻¹² but few interventions have been developed to help clinicians improve communication with families of patients with advanced cancer.¹³ Rather, most interventions involving families of patients with

advanced cancer have focused on improving family caregivers' knowledge, burden, or quality of life by building coping skills or patient-family communication skills.¹⁴⁻¹⁷ A recent intervention to improve physician-family communication involves identifying family caregiver type to allow oncologists' tailoring of their communication with family,¹³ but the intervention does not directly address how oncologists should communicate, nor what topics should be discussed, with family. We found that most patients highly value oncologists' communication with family members and recommend that communication training for oncologists should also specifically address the benefits and challenges of communication with family.

A theme identified by both patients and oncologists was the symbiotic nature of emotional responses between patients and families and the desire of patients and families to protect each other's feelings. Other studies have also found that patients or family may want to protect each other's feelings and that patient presence may be associated with decreased emotional expression by family members during family conferences for advanced cancer patients.^{18,19} Both patients and oncologists in our study recognized that patients' and families' emotions and their effects on each other can make GoC conversations difficult for both patients and oncologists. Emotional distress can be high for patients and family during GoC conversations, and oncologists need to be able to manage these emotions to effectively guide GoC conversations. While current communication training for oncologists addresses managing patient emotions,^{20,21} training should also specifically highlight managing families' multiple and different emotions. Furthermore, patients also described the impact that cancer had on family, and oncologists should be aware that patients often may try to protect family members from knowing the complete details of their illness or treatment in an effort to protect families' feelings and to minimize the impact of their illness on family.

Another theme identified by patients but not by oncologists was the family's relationship with the oncologist. While there has been some discussion of the triadic nature of the patient-family-oncologist relationship,^{5,6,10,22,23} little has been written about the impact of the oncologist-family relationship on the oncologist-patient relationship. We found that patients valued oncologists who took the time to speak with multiple family members and who could speak at different levels depending on family members' knowledge and emotional status. It is important for oncologists to recognize that not only their direct relationship with patients but also their relationship with patients' family impacts their patients' comfort and confidence in them.

4.1 | Study limitations

We purposively sampled patients with a range of different cancers on varying lines of therapy in diverse geographic settings, as well as oncologists who practiced in different settings to obtain a wide breadth of data. Our findings may not be generalizable to a larger group of advanced cancer patients and oncologists; however, several of the themes we identified have been noted in previous studies regarding the influence of family involvement in decision-making for patients with cancer.

4.2 | Clinical implications

Family involvement can enhance GoC conversations with patients with advanced cancer, but oncologists need to address the challenges that can arise with family involvement. Oncologists should be aware of patients' views about family involvement over their illness course, patients' concerns about how their cancer may affect family, as well as family expectations for patients' treatment goals. Education in how to manage differing opinions and emotions may help oncologist be most successful in guiding these potentially challenging conversations.

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