



## Cancer clinical trial providers' perspectives on communicating goals of care: A key informant study



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### ABSTRACT

**Objectives:** There has been limited research to date exploring provider communication in the context of cancer clinical trials. To elucidate multidisciplinary care providers' experiences, this qualitative study sought to understand their perspectives and communication patterns around goals of care discussions with patients enrolled in cancer clinical trials.

**Methods:** Semi-structured key informant interviews were conducted with a purposive sample of physicians, nurse practitioners, social workers, chaplains, nurses, and administrative staff in a cancer research hospital (N = 19). Data were analyzed and interpreted using thematic analysis.

**Results:** Providers hold varied perspectives on goals of care in cancer clinical trials, highlighting the tension and potential for misalignment between scientific and clinical (patient-centered) goals. Inherent institutional hierarchies may impede some team members from initiating goal discussions. Care transitions (e.g., stopping treatment or initiating hospice) offer critical opportunities for goals of care discussions.

**Conclusion:** Conflicting perspectives among team members, perceptions of provider roles, and communication patterns could help explain some of the communication challenges previously documented in advanced cancer and clinical trial care.

**Innovation:** This qualitative study contributes to the literature on healthcare team communication in the clinical trial context and highlights tangible opportunities to better leverage providers' diverse experience and improve patient-centered care.

### 1. Introduction

Recent advances in cancer treatment, including immunotherapy and targeted therapies, offer the promise of better outcomes for patients diagnosed with advanced cancer [1,2]. Many cancer clinical trials recruit patients with poor prognoses whose disease is not responding to standard treatments. Once enrolled in trials, patients often face communication challenges and a sense of uncertainty as their providers try to find a balance between expressing enthusiasm about innovative treatments while also conveying the reality that the disease may not respond to the experimental treatment and that there is a possibility of unknown side-effects [3]. The situation is further complicated by "therapeutic misperceptions" [4]: patients often enter trials believing that they are likely to benefit personally [5-7], and are unrealistically optimistic about treatment efficacy [5,6,8,9]. For example, a study on Phase I clinical trials found that patients predicted a significantly higher likelihood of benefit from treatment than their physicians,

suggesting discrepancies in understanding and suboptimal patient-provider communication [10]. A more recent study found limited disclosure regarding the purpose of Phase I trials by principal investigators to advanced cancer patients during evaluation [11]. The potential for unrealistic expectations or inadequate communication to foster misperceptions about trials presents ethical concerns. While federal regulations require participants to give informed consent acknowledging their understanding of the risk and potential personal benefit (or lack thereof) associated with clinical trial participation, experts acknowledge that often this goal is "imperfectly realized" in practice [12]. The inevitable state of uncertainty and the possibility of misaligned understanding of clinical trial goals underscores the importance of patient-centered communication in this context.

To date, research on patient-centered communication in cancer care has tended to focus on patient-oncologist dyads. In particular, discussions about **prognosis** (defined as *the probable course or outcome of a disease*) and **goals of care** (*the purpose of the patient's current medical care*) are seen as central to

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successful clinical interactions [13]. Given that many patients have shown limited understanding of their prognosis [14-16], and that significant misalignment regarding prognosis is often observed between providers, patients, and caregivers [17,18], it is important for oncologists to make a conscious effort to effectively communicate their knowledge of the patient's health status, ascertain the patient's preferences and goals, and support the patient and their family in making decisions about care [19,20].

Although the above-mentioned research has identified several key communication issues between oncologists and patients with advanced cancer, a major gap in the literature exists regarding communication across all providers and teams that are integral to day-to-day patient care. This is especially true in the care of patients enrolled in clinical trials, since they see multiple providers and interact with multiple care teams on any given day. When different providers' perceived goals of care do not align, the risk for confusion is high, and patient-centered care may be jeopardized. As an example, a 2019 study in the surgical context (where patients are typically cared for by many different clinicians during their hospital admission) demonstrated conflicts over patient goals of care between clinicians [21].

In recent years, the concept of "multidisciplinary (care) teams" has been examined [22]. A meta-analysis demonstrated that "shared mental models" among team members impact relationships, processes, and, in turn, team performance [23]. Other studies have attempted to identify components of a functioning cancer care team and understand how they contribute to measurable patient outcomes [24,25]. These investigations pointed to the importance of well-delineated member roles and tasks, responsibility assignment, and agreed-upon processes. However, despite improved understanding of health care teams, more empirical research centered around critical care transition points such as goals of care discussions and clinical trial decisions is needed.

### 1.1. Purpose

Using semi-structured key informant interviews, this qualitative study describes how multidisciplinary clinical trial care providers define, operationalize, and communicate about goals of care. The main objectives of this study were to elicit and synthesize: 1) providers' understanding of goals of care in clinical trials; and 2) their experiences communicating about goals of care, with both colleagues and patients, particularly when managing changes in care. Such an exploratory approach to studying provider communication regarding goals of care can help generate critical information on team functioning and identify opportunities for improved communication within and across teams, as well as between providers and patients.

## 2. Methods

Grounded theory [26] and inductive approaches guided the study design and subsequent qualitative thematic analysis. We conducted a series of 19 semi-structured key informant interviews in 2016 with a purposive sample of multidisciplinary care providers at a U.S. teaching hospital. We recruited a convenience sample with the goal of including a wide range of provider roles as well as having several informants within each role in order to obtain multiple perspectives. The study was deemed exempt from IRB review by the authors' institution. After receiving approval from hospital leadership, we asked the heads of two clinical teams to nominate staff members, and we sought consent from these individuals to participate in key informant interviews. Informants represented a range of disciplines, including principal investigators/attending physicians (hereafter PIs), medical oncology fellows, research nurses, patient care coordinators, and social workers. Subsequently, seven additional providers that were not formally part of these research teams, but whose patient care roles were deemed critical by our initial informants, were also contacted for consent to be interviewed. These included two palliative care fellows (PCFs), two clinical nurses, a pharmacist, and a chaplain. Table 1 describes the final sample of informants by role.

**Table 1**

Description of informants' roles on care teams

Team 1	<ul style="list-style-type: none"> <li>• Attending Physician/Principal Investigator (PI)</li> <li>• Oncology MD Fellow (OF)</li> <li>• Research Nurse (RN)</li> <li>• Nurse Practitioner (NP)</li> <li>• Program Administrator</li> <li>• Social Worker (SW)</li> </ul>
Team 2	<ul style="list-style-type: none"> <li>• Attending Physician/Principal Investigator (PI)</li> <li>• Oncology MD Fellow (OF)</li> <li>• Research Nurse (RN)</li> <li>• Physician's Assistant (PA)</li> <li>• Patient Care Coordinator (PCC)</li> <li>• Social Worker (SW)</li> </ul>
Other Care Providers	<ul style="list-style-type: none"> <li>• Clinical Nurse-outpatient (2) (CN)</li> <li>• Clinical Nurse-inpatient (CN)</li> <li>• Chaplain</li> <li>• Pharmacist</li> <li>• Palliative Care Fellow (2) (PCF)</li> </ul>

Semi-structured interviews were conducted in person (n = 17) and by phone (n = 2) and lasted 22.3 minutes (SD = 7.88) on average. The interviews, led by a senior author and observed by another author, followed an Interview Guide (Fig. 1), which had been pre-tested iteratively with three practicing clinician-researchers. All interviews were audio-recorded, professionally transcribed, accompanied by observers' detailed field notes, and de-identified to preserve informant anonymity.

The study utilized a data-driven inductive approach to thematic analysis. A codebook was generated through an iterative, team-based process [27] where transcripts were reviewed and annotated by team members. High-level topics were drawn from the interview probes, whereas emerging themes (e.g., the different goals for clinical trial care, or different meanings of palliative care) were identified and categorized through an exhaustive transcript review. Final codes for the identified themes were operationalized through a consensus building process and then revised for parsimony. The final codebook consisted of 11 high-level codes and 133 unique sub-codes. This codebook was piloted in two rounds of double-coding four transcripts to identify and resolve coder discrepancies and train coders for maximum consistency. The coders then independently coded remaining interview transcripts. NVivo, Version 10 was used to conduct data analysis.

## 3. Results

Cancer clinical trial care providers expressed a diverse range of perspectives about the meaning of goals of care and their experiences communicating about goals of care with colleagues and patients. The main findings are organized around three major topics elicited in the interviews: 1) understanding and perception of goals of care ; 2) reported processes for discussing goals of care with patients; and 3) management of changes or transitions in patient care (e.g., hospice referral, stopping a treatment protocol, etc.). Key themes identified under each topic (**in bold**) are described in greater detail below. Deliberate attention was given to maximizing representation across roles in illustrative examples provided for each theme.

### 3.1. Topic 1: understanding of goals of care in cancer clinical trials

Informants' descriptions of clinical trial goals of care fell into two overarching themes: **scientific goals** and **clinical goals**. Informants frequently commented on the challenges of managing the delicate balance between these two sets of goals, as well as the differential emphasis placed on extending life vs. maintaining or improving patient quality of life and providing palliative care. Fig. 2 summarizes the varied goals that were mentioned in the interviews, along with illustrative quotes (all quotes are labeled with the respondents' role and the interview guide question they were responding to).

The scientific goals of care described included: **contributing to scientific discoveries**, **adhering to treatment protocols**, and simply **providing the treatment** to a patient. The clinical goals mentioned included:

- Q1. Please describe your **typical patient population** on the [ ] unit.  
 a) We are interested in the different ways in which you **interact with the patients**.  
 Could you tell me about **your typical day** on the [ ] unit?
- Q2. We are interested in learning about your **interactions with your team**. Can you briefly describe who you consider as part of your team? What is your specific role in the team?
- Q3. In this project, we are particularly interested in the communication related to a **patient’s prognosis and goals of care**.  
 a) When I say “goals of care”, what does that mean to you?  
 b) Follow-up: Could you tell me about the **range of goals and priorities** you may have for a patient’s care?
- Q4. Now, consider a **hypothetical scenario**: If you were a patient here at the (hospital name), what would be most important to you? What would your goals be?
- Q5. We would like to consider a scenario in which your patient enrolled in a treatment protocol **needed a change in their care**. For example, a patient’s worsening symptoms (e.g., due to toxicity) suggest a need to have a hospice referral or end-of-life care. Can you talk about how such a situation is handled (i.e., typical steps that occur, and your role in these situations)?
- Q6. Finally, what does **“palliative care”** mean to you in your current role?  
 a. Follow-up: How do you go about obtaining palliative care for your patient? [probe]  
 b. Who is involved in this process?
- Q7. Is there anything else that you think that we should know? [additional follow-up prompts]

Fig. 1. Interview Guide: List of questions asked of key informants

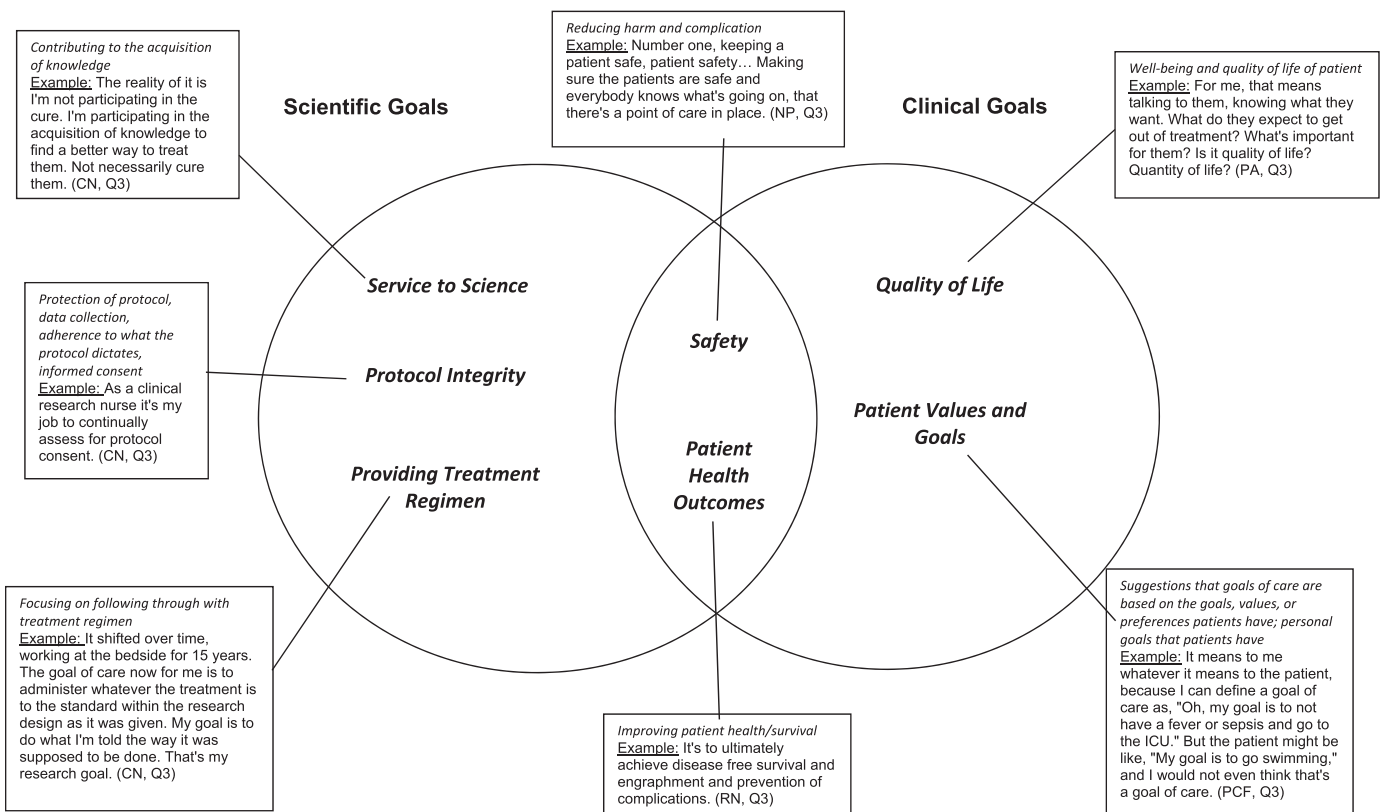


Fig. 2. Different goals of care described by clinical trial care providers, supported with illustrative quotes

**maintaining quality of life** for the patient and **aligning care with the patient's personal goals**. Some goals, such as **maintaining safety/minimizing harm**, and **improving patient health**, fell into both the “scientific” and “clinical” categories. A few informants noted that it is when scientific and clinical goals are aligned that optimal clinical trial care is achieved. For example, one PI noted, “I try to make sure that the clinical best interests of the patient are what dictate what (we) do.” He described the patient's interests as not always “in line with (research)”, which creates the need “to be very honest with yourself and with the patient.” Other informants similarly highlighted the distinction and tension between scientific and clinical goals when discussing their work caring for patients. For example, one of the research nurses noted that “There's a big discussion about clinical versus research. I think that they go together a lot. (But) it's a lot of gray area.”

To better understand this “gray area,” we further examined responses pertaining to the theme of **goal misalignment**. The data suggest that misalignment in goals of care is often rooted in institutional hierarchy, and specifically, the PI's decision-making authority and responsibility. For example, one social worker described the PI as “the one that decides - because of protocol, guidelines - what the possible medical goal can be.” The same social worker described her own role in handling situations where the protocol and patient goals are misaligned as follows: “If the PI has certain goals, but the patient accepts a few but not others, then that's where we intervene and see, is it a different goal that they want to add?” Similarly, clinical nurses, who are not part of the research team, spoke about being patient advocates and conveying patients' concerns and preferences to the research PIs. For instance, one clinical nurse stated that she acts as a liaison between the patient and the research team: “I usually report it [a need for support services] to the team caring for the patient and then they communicate with the primary investigator if needed.”

Hierarchy was also reflected in the perception that in the context of cancer clinical trials, members of the research team, as opposed to providers not directly engaged in research, had the authority to make decisions regarding treatment. A palliative care fellow, describing situations where perceived goals of care are misaligned, suggested that the research team may not be prepared to discuss shifting goals and therefore engage with the palliative care team only regarding symptom management: “The [research] team sometimes will say, ‘I'm asking you about her jaw pain. We're not quite ready to talk about end of life.’” This quote illustrates, in part, the inherently hierarchical context within health care settings (in this case, the fact that the research team's decision supersedes other providers' priorities) and its impact on communication around goals of care. This context may make providers in certain roles reluctant to question decisions made by PIs, and prevent them from advocating for what they believe to be in the best interest of the patient.

In addition to disagreements between providers, several informants reported internal conflicts about goals of care, such as struggling with continuing treatment in certain situations, and having difficulty engaging in discussions about end-of-life care with patients because it would be perceived as “giving up” (PI). For example, one palliative care fellow described grappling with the pressure to adhere to the protocol by providing certain medications that might compromise the patient's quality of life, which was in conflict with his belief in the importance of seeing “the patient as a whole person”. A PI spoke of internal conflict when a patient's disease is not responding to treatment: “When they come and they sign the consent, they know that their back is against a wall... there is ongoing tension between how hard you push. Are you deceiving yourself?”.

### 3.2. Topic 2: communicating goals of care with patients

The diverse conceptualizations of clinical trial goals of care have critical implications for how, when, and what goals are communicated to patients. Experiences with patient communication were elicited as informants responded to probes about scenarios of care transitions. Key themes that emerged, along with illustrative quotes, are compiled in Table 2 and further explained below.

**Table 2**

Informants' descriptions of their communication with patients and caregivers about goals of care

Themes	Illustrative Quotes (informant role, corresponding interview guide question)
Listening to patient understanding of prognosis and goals of care	<ol style="list-style-type: none"> <li>1. I remember another situation. It was very early, I just gotten here. I entered a patient room and she's sitting in the dark. Within about three minutes, she's telling me that she's not sure that continuing on protocol is going to do anything for her, and that she's thinking about what her epitaph is going to be and that maybe she just needs to quit. (Chaplain, Q2)</li> <li>2. I know we have conversations about “in the event that I get into a medical crisis. Are we or are we not going to call a code? Intubation is that something I think is in my best interest or not, is there a particular time frame?” It's like, “Yeah, I would really like to live, so if I get into a crisis, please do intubate me, but I don't want to stay there long term. If I'm not progressing, then we might be talking about withdrawal of support and end-of-life...” [or] “What's important to me now is that my symptoms are managed as well as possible so that I can be in a position to maybe communicate with the people whom I love the most, maybe get home so that I can say some goodbyes. I only have a couple of months life and what I really want to do I can't do while I'm here in the clinical center. I want to be at home.” That's the goals of care... the research, while crucially important, really can't override what is in this person's interest in that we might need to be listening to that and helping them, maybe not to continue on protocol but to transition to their home environment... (Chaplain, Q3)</li> <li>3. There's actually someone I can think of right now that's currently inpatient. After the medical team decided that, just medically, she's not doing as well as they expected, and the medication hasn't been as responsive, they approached the patient and tried to be like, “This is the situation. How do you want us to move forward as well?” “We have this option of trying something extra with these risks, or we can send you home with these risks, ultimately being hospice or, just comfort care.” Because I go to rounds every... I know this patient. Then I check in on her, so I know what's been going on, that the team is like, “Listen, we spoke to her today, gave her details of both kind of options. You might want to check in with her because she now knows.” That just gives me the open door to go in there and be like, “So this was discussed. What do you think?” Really help her process what she's thinking, and weigh out the pros and cons with her in a more personal level, and not medical level. (SW, Q5)</li> </ol>
Eliciting patient values and preferences	<ol style="list-style-type: none"> <li>4. I always ask the patient, “What are you hoping for? OK, then what else are you hoping for? What else?” and get through the layers. Because there's a goal and there are sub-goals. A lot of times, the goal I'm hearing is not actually realistic sometimes. Being like, “OK, what else is your goal? What else are you hoping for?” Then you could reach something that's doable. (PCF, Q3)</li> <li>5. For me, that means talking to them, knowing what they want. What do they expect to get out of treatment? What's important for them? Is it quality of life? Quantity of life? (PA, Q3)</li> <li>6. the check in of where the family and patient are in regards to how the care is going. What are they doing? Is this along the lines of what they were thinking about, hoping for? (PCF, Q3)</li> </ol>

Table 2 (continued)

Themes	Illustrative Quotes (informant role, corresponding interview guide question)
Communicating with family caregivers about goals of care	<p>7. <i>There are certainly times when it's been somebody's mom, somebody's spouse, somebody's children that I have had the focus of my relationship rather than the patient themselves. I certainly want to communicate that when I walk into a room...get a sense for what their relationship is. That's also a piece of how they're being impacted in terms of sense of meaning, purpose, allegiance and all of those things.</i> (Chaplain, Q7)</p> <p>8. <i>All the time, when we do the consenting process, I always say that to patient, "You have the right to withdraw from the study at any time. But we ask that you talk to us first before doing so." A lot of times with the transplant patients, they're here till the end. Some of them pass away here, and some of them pass away at home. Whether that be with home hospice or they go to a hospice facility. These are the difficult conversations that the providers have with family members and the patient themselves. They have to see what their wishes are. These are conversations that the PIs have. The principal investigators have with the patients. Research nurse or a mid-level might say, "Hey, patients concerned, the family members are concerned." These are difficult conversations and sometimes family members, they don't want to say something, or they're trying to say something in front of a whole group of doctors... We definitely get the input of the patient and the family members.</i> (RN, Q5)</p>
Approaching goals of care conversations with honesty	<p>9. <i>A lot of our (doctors) are very honest with these patients. "You have that X number of months if you don't do this." "This may or may not work for you. It's Phase One, Phase Two." I feel like our patients get that when they sign up for protocol but sometimes in the back of their mind they don't always accept that this is research, so that's one of the things that I've seen too.</i> (CN, Q4)</p> <p>10. <i>Those are situations where I feel like you have to be very honest with them about their circumstance, their options.</i> (PI, Q5)</p> <p>11. <i>Honestly if we think that a patient should go to a different study that would benefit for them, we've done that. We've sent people to other studies, we've sent people for other treatments. We said, "Look, we believe in what we do but obviously it's not working for you." We do that. We're pretty honest with our patients and they like that. They do appreciate that.</i> (PI, Q4)</p>

Informants recounted **listening to patients' explanations of their goals**. The personal account in example quote (1) shows the vividness of the experience of talking to a patient who is deeply reflective about her end of life and decision-making about trial continuation. The majority of informants across roles described **attempts to elicit patient preferences**, hallmarks of communication about goals of care. For instance, examples (4, 5) illustrate the questions providers used to elicit their patients' goals of care. As shown in example (7), informants also talked about **communicating with family caregivers**, and the importance of understanding family relationships and dynamics. Finally, as illustrated in examples (9, 10), faced with potentially conflicting goals in the context of a poor prognosis, four informants specifically referenced the **importance of honest and open communication**. Providers also acknowledged a common tendency for patients

to regard cancer clinical trials as an opportunity to cure their disease, rather than a research study that may not provide them with direct benefit (example 9), and highlighted the need to be honest with patients in these circumstances (example 10).

### 3.3. Topic 3: descriptions of changes in care

We elicited accounts of specific scenarios in which a patient needed a change in care (often due to worsening symptoms or disease progression), as accounts of personal experiences have been shown to effectively reveal attitudes, perceptions, and experiences that are otherwise difficult to elicit with closed-ended questions [28,29]. The common types of changes described by informants included sending patients back to primary or oncology care, referring them to hospice, finding a new protocol for them, and sending them home. The challenges of managing these changes were emphasized in informant responses. Key themes related to changes in care are presented in Table 3 and further described below.

A key challenge noted by informants concerned the timing of goals of care conversations, particularly how making decisions about appropriate care is — or should be — an *"ongoing discussion"* (example 1). The **tension, disagreement, and confusion between different providers (example 2 and 4)** and the **tension between providers and patients (examples 5 and 6)** were also highlighted. Specifically, discussions about who should initiate the transition or plan for hospice admission and the timing of these transitions all create tension. Informants reported that these **discussions were emotionally taxing** and described the experience of witnessing patients ending protocol participation as *"troubling"* (CN) and *"stressful"* (PI) (examples 7, 8).

The way informants described changes in care highlighted the stark contrast between scientific promises of a protocol and patients' poor prognoses. For example, one PI described himself as being motivated to *"keep going"* (with a treatment protocol), having seen *"dramatic success stories"* despite patient's dire disease status: *"...if we're investigating a very radical or new type of treatment...it gives us motivation to keep going, if we see some of these very dramatic success stories even in these tough patients.... Obviously, it's very stressful for the team to have to deal with these things [i.e., seeing patients not respond to treatment]."* (example 8).

In the common situation of worsening disease and the need to transition to end-of-life care, decisions to stop treatment trial participation are often complex and difficult. The research team members commented on experiencing conflict with the palliative care team about whether to stop a protocol, feeling the urge to push back at the suggestion to transition to palliation-oriented care instead of continuing the trial protocol; for example, one PI noted that *"There is no real animosity there, but there is ongoing tension between how hard you push"*. Additionally, informants talked about patients' wish to remain in the hospital despite not responding to a treatment protocol. In particular, a research nurse suggested that some patients have resisted leaving even after stopping treatment protocol: *"they're here till the end. Some of them pass away here... a lot of these patients have been coming here for years... (they) have a lot of security here, I think. They want to stay here."* This continuity of care seems to give patients and providers a sense of comfort.

## 4. Discussion and conclusion

### 4.1. Discussion

Research consistently demonstrates that discussion of goals of care with patients experiencing serious illness is associated with beneficial outcomes, and that failure to address goals of care can lead to harm, including the delivery of care that is not consistent with patient goals and worse quality of life [19]. However, to date, little attention has been paid to goals of care discussions in the context of clinical trials. The findings of this study highlight several key challenges in achieving patient-centered clinical trial care. The observed tension between wanting to help extend a patient's life and supporting critical research while ensuring that the patient's personal goals, values, and quality of life are maintained emerged as a central

**Table 3**  
Informants' descriptions of managing changes/transitions in care

Theme	Illustrative Quotes (informant role, corresponding interview guide question)
Tension and confusion between providers	<p>1. <i>It is an ongoing discussion... We have some patients that they (other providers) want to put on palliative and we want to keep pushing. We are always negotiating.</i> (PI, Q5)</p> <p>2. <i>...Hey, the patient's dying and I realize that nobody on your team is saying that.... How can we make them comfortable without you (research team) feeling conflicted?' .... I will be leaving notes in the chart: 'The patient has disease progression. They're going to come off protocol'. The primary team puts in their chart, 'Talk about hospice. We told her this disease progression, reviewed imaging results with her.' I go in the room and I'll say, 'What do you know?' The patient is like, 'I don't know.' Did you acknowledge that she's not hearing you because she's so shell-shocked?'' (PCF, Q2/5)</i></p> <p>3. <i>...so if you're a consultant as a palliative care doc, and you're trying to tell the primary team that this is what this change in plan for a patient. A patient said that they want to change their plan, increase their care, decrease their care, but the primary team is not ready to hear that, yet, or they're not wanting to hear that, yet, because they had high hopes or plans for other things. I think that's where communication might not be received well or might not even be heard, and then, things break down from there.</i> (PCF, Q7)</p> <p>4. <i>There's a lag sometimes I've noticed unfortunately in what nurses think patients have had enough and sometimes what primary investigators have thought.</i> (CN, Q6)</p>
Tension between patients and providers	<p>5. <i>We'll get a sense that a patient may be having to come off study in the days and weeks coming up and we don't hopefully spring it on them in one visit ... We'll be like, "Last time we mentioned that if the numbers keep coming up... we believe it would be in your best benefit to consider other options."</i> (OF, Q5)</p> <p>6. <i>They'll ask me specifically about the studies, their outcome, have there been any results. I can't really provide them with that information. Sometimes the doctors and the fellows can't even provide them with that information. It generally tends to come from the newer patients.</i> (PCC, Q3)</p>
Emotional impact of transitions	<p>7. <i>It was very very troubling initially for me. What do you do when you have a patient that's on therapy for a year-and-a-half, and it stops working? What happens to them? Where do they go? They go back to their physicians, and whether they transition back home to wherever they're from? Some cases, that's it.</i> (CN, Q5)</p> <p>8. <i>If we're investigating a very radical or new type of transplant, it's OK for us, because we're still in the exploratory stages, and we've had successes against some of these diseases. It gives us motivation to keep going, if we see some of these very dramatic success stories even in these tough patients. It's been very good for us. It creates a difficult work environment. Obviously, it's very stressful for the team to have to deal with these things.</i> (PI, Q1)</p> <p>9. <i>Again, these people come in with great hope so it's really hard to get that out there to them that we have nothing else to offer you.</i> (CN, Q6)</p>

theme across the interviews. While the tension between different care goals might exist in other health care contexts (e.g., [30,31,32]), it may be magnified in the cancer clinical trial setting, where many patients have advanced and complex disease. Here, it is important to emphasize that although tension was observed within and across teams, this interview study does not point to evidence of miscommunication. PIs described careful attention to communicating care goals with patients. While most clinicians have room to improve their communication practices, the data by no means suggest a breach of clinical equipoise.

The study also illustrates the diverse and even divergent perceptions and definitions of goals of care among providers. Although previous research has documented disagreements on goals of care between different healthcare team members (e.g., [21]), the nature of these disagreements may be different in the clinical trial context. We found that those closely involved in research (e.g., PIs, fellows, research nurses) may tend to focus on the scientific goals of the trial, while other care team members (e.g., clinical nurses, social workers, chaplains, palliative care physicians) may focus more on patients' personal concerns. Tensions can arise when these goals are not aligned or not adequately communicated. Effective use of team-based approaches, namely, enabling team members to develop and cultivate shared mental models while also comfortably discussing their diverse viewpoints would likely improve patient-centered care.

The observed challenges in goals of care communication may, in part, explain some of the established challenges in advanced cancer. Numerous studies have reported poor patient-reported quality of life, emergency room visits, overuse of curative chemotherapy, and under-utilization or delayed introduction of palliative care services [17,18,33]. While these outcomes are well-documented, there have been few systematic attempts to explain the root causes of these problems. Observational studies, such as the present work, can begin to offer insights into typical care trajectories (e.g., stopping a protocol or moving to a new protocol, sending a patient home) for patients and the conflicting goals being negotiated throughout trial participation as patients' health status changes. Informants' descriptions of these (often emotionally charged) transitions point to key sources of tension within and across teams.

The avoidance of discussions about patient values and goals of care in advanced illness is attributable to barriers at multiple levels, including providers' fears of disappointing patients or damaging the patient-provider relationship, socio-cultural taboos associated with discussing end-of-life, and a lack of institutional incentives (reimbursement or otherwise) to have these conversations [34,35]. Taken together, the findings illustrate the multilevel barriers (and potential solutions) to optimal goals of care communication within the cancer clinical trial context. On an individual level, providers discussed internal conflicts in initiating goals of care discussions, the emotional impact of these conversations, and their desire to help maintain their patients' hope. On a structural level, the data revealed perceived decision-making hierarchies. In addition to the authority and responsibility of the attending physicians/PIs, hierarchy is also reflected in the fact that the members of the research team may be perceived as having greater authority and opportunity to engage in goals of care discussions and treatment decision-making as compared to other providers. This was suggested in comments from a palliative care fellow, a social worker, and a chaplain, which all conveyed that they did not believe they had the authority to engage in goals of care discussions with patients enrolled in trials. In line with previous research [36-39], these observations point to opportunities for engaging more members of the care team in goals of care discussions and providing greater support for nurses and allied health professional in these conversations [37-39]. A recent analysis of a goals of care conversation initiative at the Veterans Health Administration suggests that expanding interdisciplinary providers' roles in goals of care conversations requires a culture shift at the healthcare organization, needs to be supported across layers of leadership, and benefits from clarification of expectations as well as dedicated training to enhance provider readiness [40].

Finally, this study has several limitations. First, the purposive, convenience sampling approach may introduce selection bias and therefore the views may not reflect those of other members. While findings may not generalize to other teams or contexts due to the small number of respondents in each role (e.g., PI, pharmacist), our decision to interview informants with a wide variety of roles offers a useful illustration of a range of common understandings of goals of care and challenges when goals are misaligned, as well as the difficulties of care transitions. Additionally, self-reported interview data may offer only partial assessment of team communication, particularly concerning participants' recall, motivations, and the general decision-making processes. For instance, while participants suggested that institutional hierarchy affected communication about clinical trial goals, the

data are insufficient for characterizing or evaluating team functioning systematically. These qualitative findings need to be complemented by other quantitative, qualitative, and experimental data collection approaches. Lastly, we only interviewed care providers; understanding patient and caregiver perspectives about goals of care is the next logical step in order to gain a comprehensive view of goals of care across all those who are involved in clinical trials.

#### 4.2. Innovation

The study's innovation lies in its examination of the entire care team and their personal experiences, the focus on the clinical trial context, and the clinical implications stemming from the findings. First, by eliciting goal communication experiences of diverse members of the care team (including social workers, chaplains, nurses, and administrative staff), this study provides a unique contribution to the literature which has largely focused on physicians or on the patient-provider dyad. Second, the focused inquiry into the clinical trial context (as opposed to general oncology care) provides unique insights into the dynamics and challenges present in an understudied clinical setting that provides care for many advanced cancer patients who face limited treatment options and who have elected to enroll in a trial.

In terms of clinical implications, the study underscores the importance of efforts to facilitate team communication to ensure that the experiences, perspectives, and expertise of each team member are leveraged. For example, social workers and chaplains may be more attuned to a patient's psychosocial concerns and worries, but they are not often present at goals of care or treatment transition discussions led by the PI. Team leadership may seek ways to further engage these providers' expertise by bringing them into critical discussions or having them counsel patients before, during, or after the appointment with the PI. In other words, there may be opportunities to complement or improve dyadic patient-provider goals of care conversations. Moreover, the identified varied goals and communication patterns may also help guide communication intervention development in advanced cancer and clinical trials. Ultimately, interventions must go beyond addressing providers' behaviors to account for the institutional context, including guidance from ethics review boards (regarding informed consent processes and the importance of maintaining clinical equipoise in clinical trial patient care), as well as support for patients and caregivers.

#### 5. Conclusion

Members of multidisciplinary care teams offer unique insights into the intricate dynamics within clinical trial teams charged with both scientific and clinical responsibilities. Methodologically, the study demonstrates the utility and added value of ethnographic interviews to elicit the experiences and perceptions of providers about their communication within care teams and with patients. These nuanced insights can only be obtained through qualitative approaches.

Study findings point to providers' need to manage a delicate balance between multiple (and sometimes misaligned) goals associated with the trial protocol as well as the patient's values and preferences. The inherent hierarchies and goal conflicts among team members must also be considered before each provider's contribution to patient-centered care can be optimized. In addition to team dynamics, findings also identified challenges providers face in communicating about goals of care with patients. Many reported struggling with discussions about end-of-life and patient concerns. Future work should test team-based provider training and support to facilitate these difficult conversations. Towards the goal of leveraging care teams' diverse expertise to elicit and address patient preferences, team-based goals of care communication interventions hold the potential to improve communication. Such efforts are particularly important in the context of clinical trials and in care transitions, where all members of the team may effectively serve as advocates for the patient's values, preferences, and priorities.

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#### Declaration of Competing Interest

None

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