

Oncologists' Strategies and Barriers to Effective Communication About the End of Life

By Leeat Granek, PhD, Monika K. Krzyzanowska, MD, MPH, Richard Tozer, MD, and Paolo Mazzotta, MD

Ben Gurion University of the Negev, Be'er Sheva, Israel; Princess Margaret Hospital; Sunnybrook Health Sciences Centre; University of Toronto, Toronto; and Juravinski Cancer Centre, Hamilton Ontario, Canada

Abstract

Purpose: Communicating about the end of life with patients has been reported as one of the most difficult and stressful part of the work of oncologists. Despite this fact, oncologists receive little training in this area, and many do not communicate effectively with patients. The purpose of this analysis, part of a larger study examining oncologists' experiences of patient loss, was to explore oncologists' communication strategies and communication barriers when discussing end-of-life issues with patients.

Methods: Twenty oncologists were interviewed at three hospitals about their communication strategies on end-of-life issues with patients. The data were analyzed using the grounded theory method.

Results: The findings revealed the strategies to effective communication about the end of life included: being open and honest; having ongoing, early conversations; communicating about

modifying treatment goals; and balancing hope and reality. Barriers to implementing these strategies fell broadly into three domains, including physician factors, patient factors, and institutional factors. Physician factors included difficulty with treatment and palliation, personal discomfort with death and dying, diffusion of responsibility among colleagues, using the "death-defying mode," lack of experience, and lack of mentorship. Patient factors included, patients and/or families being reluctant to talk about the end of life, language barriers, and younger age. Institutional factors included stigma around palliative care, lack of protocol about end-of-life issues; and lack of training for oncologists on how to talk with patients about end-of-life issues.

Conclusion: We conclude by drawing implications from our study and suggest that further research and intervention are necessary to aid oncologists in achieving effective communication about end-of-life issues.

Introduction

Communicating about the end of life with patients has been reported as one of the most difficult and stressful parts of oncology.¹⁻² Although this type of communication is a central part of the work oncologists do, it is well established that oncologists receive little training in this area,²⁻⁴ and as a result, many do not communicate these issues effectively with patients.⁵⁻⁷ The ability to communicate well is important to good patient care and has been associated with greater patient satisfaction, better patient outcomes, less patient anxiety, better adherence to treatments,⁸ and better care at the end of life.⁹⁻¹⁰

Barriers to effective communication about the end of life have been examined in other disease specialties. For example, physicians treating AIDS reported communication barriers around end-of-life issues that included discomfort discussing death, belief that discussing death would harm the patient and/or undermine their hope, lack of time to discuss such issues and physician belief that the patient is not ready to die.¹¹⁻¹² Another study looking at health care providers in internal medicine found four main barriers to communicating about the end of life with patients that included themes related to patients, the health care system, health care providers, and the nature of the dialogue.¹³

Despite the fact that communicating about the end of life is an ubiquitous part of oncologists' work, many oncologists have reported difficulties in delivering this information to patients

and their families.¹⁴⁻¹⁶ The purpose of this analysis, which was part of a larger study examining oncologists' experiences of patient loss,¹⁷⁻²⁰ was to explore oncologists' communication strategies and communication barriers when discussing end-of-life issues with patients.

Methods

Study Participants

Twenty oncologists were recruited and interviewed between November 2010 and July 2011 from three adult oncology centers in Canada. Purposive sampling was used to target three groups of oncologists who were at different stages of their career trajectory and who varied in their sub-specialties, sex, and ethnicities. See Table 1 for oncologist demographics. Exclusion criteria were the inability to speak English and never having had a patient die in their care.

Procedure

After receiving ethics approval, the oncologist coinvestigators (M.K.K., R.T., P.M.) approached participants at their respective study sites via e-mail and asked if they could be contacted to hear more about the study. If the oncologist agreed to be contacted, the principal investigator (L.G.), a psychologist who did not work with the participants, followed up to describe the study and schedule an interview. A semistructured interview

Table 1. Participant Demographic Characteristics

Characteristic	No.	%
Sex		
Male	11	55
Female	9	45
Age, years		
Mean	47	
Range	30-65	
Living situation		
Married	16	80
Single	4	20
Children	14	70
Religious background		
Jewish	1	5
Catholic	4	20
Christian	8	40
Hindu	1	5
Sikh	1	5
None	4	20
Race/ethnicity		
White	14	70
Indian	3	15
Asian	3	15
Time in practice, years		
Mean	13	
Range	1.5-31	
Disease site specialty		
Breast	6	30
GI	5	25
Genitourinary	5	25
Head and neck	1	5
Hematology	2	15
Lung	1	5
Melanoma	2	10
No. of patients seen per month		
Mean	176	
Range	44-360	
Length of relationship with patient		
Range	4 weeks-25 years	
No. of patient deaths per month		
Mean	4	
Range	1-10	

guide with questions designed to encourage oncologists to discuss their experiences in depth was used. All interviews were recorded and transcribed, and all identifiable information was removed from the transcripts.

Data Analyses

In accordance with the grounded theory method, data collection and analysis took place concurrently, and line-by-line coding was used.²¹ As the analysis continued, the descriptive codes were further distilled to capture the themes and subthemes

emerging from the text. The coding scheme was revised throughout the process of data analysis and was developed through ongoing discussions with members of the research team. Data collection stopped when the team determined that we had reached saturation and that no more new codes were created. NVivo computer software was used to organize, code, and store the data.

Results

When oncologists were asked to talk about their communication strategies when discussing the end of life with patients, a number of themes arose. These included themes pertaining to how they communicated, the content of the communication, and why they chose to communicate in these ways. Tables 2 and 3 outline our findings in chart form and provide supporting quotations for each theme we report on below.

Oncologists' End-of-Life Communication Strategies

Communicating Because of Physician Responsibility

Although most oncologists acknowledged that communicating about the end of life was emotionally difficult, the majority felt it was their obligation to do so for the welfare of their patients and because it was part of their jobs.

Open and Honest Communication About the End of Life

Many oncologists talked about the importance of being open and honest when communicating information about the end of life. This did not necessarily mean giving all the information the oncologist had at their disposal, but communicating what they perceived to be the relevant information so that patients and their families knew the prognosis.

Ongoing, Early Conversations

In addition to being open and honest, oncologists spoke about the necessity to have these conversations early and often. They noted that patients sometimes could not absorb or hear this information in earlier visits where the focus for the patient and their family was on fighting the disease.

Communicating About Treatment Goals

Another strategy involved talking about treatment goals. In terms of treating patients with terminal illness or those receiving palliative care, this meant shifting the conversation from a focus on cure to a focus on providing comfort for the patient by controlling symptoms and pain and improving quality of life. Some also spoke about modifying treatment expectations and redefining the notion of success in the context of treating the cancer.

Balancing Hope and Reality in Communicating Bad News

A robust issue that came up in the context of communicating about the end of life was the need to give patients hope while making them aware of the reality of their poor prognosis.

Taking Cues From Patients

Oncologists noted that communicating about the end of life is an art and that knowing how much to communicate and in

Table 2. Practices: End-of-Life Communication Strategies by Oncologists

Theme	Supporting Quotations
Communicating because of physician responsibly	[Communicating about the end of life] is difficult in the sense that it is emotionally trying, but in terms of having the discussion . . . that has to be done at the time, and I see it helping to prepare and making sure that down the road that they know what to do. It's an educational piece of what we do.
Open and honest communication	Just by being open . . . trying not to hide things. I do not give timelines to people unless they ask me specifically. I think in terms of dealing with a palliative situation, I try to let them know this is not a curative situation, they will pass away from their cancer. I think throughout it all, it's just being open and honest.
Ongoing, early conversations	I'm pretty honest about expectations and things from the beginning, so it's not like something new . . . it's not like a bombshell or anything. It's pretty much from the first time you know that something is not curable; I think I'm very honest about telling the patients that.
Communicating about treatment goals	I say, "we're in a situation now where we're going to be able to control your symptoms, hopefully you can have an appetite, not having pain . . . but this is not something that we can expect to cure and will likely cause your death." They say, "What's the success rate?" and I say to them, "Well what do you mean by success? We have very many measures of success. That doesn't mean we can't treat it, and we have to really talk realistically about our goals for treatment." I mean these are words that I use every day of my life for my new patients.
Balancing hope and reality	I try let them know this is not a curative situation . . . on the other side of that, you don't want to take away all hope as well too, until the point where there really isn't much. So . . . you want them to be realistic but also not completely devastated. I think you do have to have good communication skills and you have to have a lot of true empathy and be able to express that well and be supportive. To be able to walk that very fine line of being optimistic and being hopeful, whereas not give people false hope or unrealistic expectations. That's a challenging thing but I think it's important. Some of my patients used to call me Dr. Death because they thought I was perhaps too negative sometimes, and I think that's probably something I've developed. I don't think you do people a favor by letting them think they're going to live forever or so I think I've probably become better in terms of balancing hope and optimism with the difficult reality sometimes.
Taking cues from patients	There's not a specific plan for discussions about death and dying. I will talk about whatever you want to talk about, and again, for things you don't want to talk about, that's okay. If they tell you that they're not comfortable with the fact that they're dying, then I guess they already know, and I don't think that it's really up to me to give them information that they don't necessarily want to hear.

what way to communicate was challenging. Oncologists often took their cues from the patients regarding the appropriate level of disclosure.

Barriers to Communication About the End of Life

Oncologists spoke about a number of barriers when it came to having end-of-life discussions with patients. These barriers fell into three broad categories: physician factors, patient factors and institutional factors.

Physician Factors

Under the category physician factors, several themes emerged that had to do with the oncologists' difficulty in communicating end-of-life information to their patients. These included the notion that treating and palliating patients was difficult for the oncologist, their personal discomfort with death and dying and their reluctance to communicate painful information; their perception of other physicians' failure to have these discussions; focusing too much on cure and treatment (ie, the "death-defying mode"), lack of experience with communicating end-of-life news, and a lack of good mentorship in modeling communication strategies about the end of life.

Treating and palliation difficult. Oncologists discussed the difficulty they had with treating and palliating a patient at the same time. These seemed at times to be contradictory goals for the oncologists, and they described this difficulty as preventing them from discussing end-of-life issues with the patient.

Discomfort with death and dying. Oncologists spoke about their discomfort with death and dying and its relationship to communicating end-of-life information, as they found it painful for both the patient

and the doctor. Some explained that the discomfort came from a taboo about addressing the end of life in the oncology context.

Team dynamics and responsibilities. Oncologists who worked on health care teams spoke about barriers to end-of-life communication as being caused by other physicians, who they perceived as reluctant to have end-of-life conversations with their patients. When a colleague did not have this discussion with the patient, the patient was not eligible to receive palliative care; thus, the lack of communication across the health care team had a perceived impact on the patient and the family.

Focus on cure and overtreatment: The "death-defying mode." Oncologists spoke about the focus on cure—what one participant called "the death-defying mode" of oncology care—as a barrier to communicating about end-of-life issues. Because oncologists were focused on curing patients, they continued to offer more interventions and treatments instead of having a conversation about end-of-life care.

Lack of experience. Oncologists noted that communicating about the end of life is something that you get better at over time and that one barrier to effective communication is simply inexperience.

Lack of good mentorship. Oncologists noted that end-of-life communication skills were gleaned from watching mentors or supervisors deliver such news in their training. One potential barrier to communication, therefore, was a lack of mentoring on how to do this effectively.

Patient Factors

Barriers to communication about the end of life sometimes came from the patients as opposed to the doctors. The themes

that arose in this category had to do with families being reluctant to talk about the end of life; patients lack of readiness to discuss death; having language barriers; and difficulty with younger patients.

Family's reluctance to address end-of-life issues. One reported barrier to communicating about the end of life with patients came from families' reluctance to face death, often times stemming from the good intention of wanting to protect their family members from information that might be painful for them to hear. Oncologists struggled with managing the families' desires with their obligation as physicians to communicate openly and honestly with patients.

Patient not ready. Oncologists explained that other barriers in talking about the end of life came when the patient was not ready to hear the news, was reluctant to have the conversation, or took the information badly.

Language barriers. Because we interviewed oncologists who are working in ethnically diverse cities, language barriers came up as a barrier to communication about the end of life. If the patient was not able to speak English, it became more difficult to communicate effectively about the end of life.

Younger patient age. Oncologists noted that the younger the patient was, the more difficult it was to have a conversation about the end of life. This was both because the patients were reluctant or unable to absorb this information and because oncologists had a difficult time delivering this difficult news to someone young.

Institutional Factors

In addition to physician and patient factors, there were also three institutional factors that made end-of-life discussions difficult for oncologists. These included a stigma around palliative care, a lack of protocol around end-of-life issues, and lack of tools and training around communicating about the end of life.

Palliative care stigma. Oncologists reported that talking about the end of life and palliative care was difficult because of the stigma surrounding palliative care services. Because some physicians and patients equated palliative care with death, some oncologists were reluctant to bring it up with their patients. Some oncologists talked about the misunderstanding of what palliative care represents and how this relates to the difficulty of communicating about the end of life.

Lack of protocol around end-of-life issues. Oncologists reported that there were very few guidelines or protocols around discussing end-of-life issues and that this was a barrier to ensuring that all patients received the necessary information about their conditions. As one oncologist remarked, "The nitty gritty of it is, it's you and your patient, and no one can tell you when to do what, right? No one can tell you [that] it's time for you to have the talk."

In order to ameliorate the individual nature of these conversations and to ensure this barrier did not prevent physicians

from having these conversations with patients, some oncologists suggested devising a protocol around how and when to have this conversation.

Lack of tools and training. Some oncologists explained that they had received no formal training or tools on how to discuss end-of-life issues with patients and that this was a significant barrier to effective communication. Although having good mentorship and experience with patient loss were described earlier under physician factors, the lack-of-tools theme captured the idea that there was a lack of training on an institutional level and that many oncologists were not educated on how to do this part of their job.

Discussion

To our knowledge, this is the first qualitative exploration of communication about the end of life from the oncologist perspective. Some of these findings have been corroborated by other reports. For example, the need for fellows or early-career physicians to be mentored in communicating about the end of life has been documented in other studies.²²⁻²³ As with our research, a few studies have reported that oncologists do not receive adequate training about discussing end-of-life issues and that specialized programs are necessary to teach these skills.^{2-4,24}

What makes our study unique is the opportunity to "get into the oncologists' heads" to understand what they perceive to be the goals of effective communication about the end of life, as well as what makes it difficult for them to achieve these goals. Through the analysis, it became apparent that there is tension between what are perceived to be good communication strategies and the significant number of barriers to implementing them. For example, oncologists reported that communication about the end of life is a dynamic process that involves a negotiation between the patient and the physician, and that at times, the cues around this communication can be challenging to read. Future studies or interventions should focus on how best to support oncologists engaged in what one participant called this "communication dance" with patients.

Physicians also spoke about the problem of diffusion of responsibility among colleagues about talking to patients about the end of life. In the context of communication, palliative care integration may be of particular relevance. A recent Provisional Clinical Opinion by ASCO looked at seven randomized control trials of palliative care interventions in the oncology context and noted, "the key tenets of PC [palliative care] include open and honest communication, medically appropriate goal setting, and symptom management."^{25(p882)} The integration of palliative care teams with standard oncology care may be a particularly effective way of supporting oncologists in communicating about the end of life in an honest and clear manner and ensuring that treatment goals are appropriately communicated. Bakitas et al looked at the oncologists' perspective on a concurrent palliative care program and found that oncologists reported personal benefits from the palliative care team intervention, especially in discussing difficult conversations with patients and

their families, such as end-of-life issues and poor prognoses.²⁶ Moreover, Wentlandt et al found that better end-of-life preparation was associated with better communication between patients and physicians, which is a key component of quality care at the end of life.²⁷ A team approach to end-of-life communication could include colleagues from palliative care, as well as other disciplines such as social work, chaplaincy, and psychology or psychiatry, so that the burden of communicating about the end of life does not rest solely on the shoulders of one physician or specialty and patients and their caregivers may have improved outcomes as was demonstrated in the randomized clinical trials.²⁶ Further study is needed on how to best implement an interprofessional team approach to communication so that patients are not lost in the fray, and so that oncologists feel supported in doing this difficult work.

Other important findings around barriers to end-of-life communication arose in the context of language, culture, and dealing with younger patients. With regard to the latter, our research indicates that oncologists are struggling with this population of patients who are not pediatric patients but are not mature adults yet, and there is a paucity of information on how to communicate with such patients. Further research is needed to assess the most effective way to communicate with these patients.

In terms of interventions, there is robust evidence to suggest that communication skills training leads to improved communication skills in health care clinicians.^{3-4,24,28-30} Several models of what this might look like have been proposed by health care professionals. Wiener and Cole⁴ put forth a model that involves three components: (1) training clinicians to manage their emotional distress during medical discussions with the dying patient, (2) helping clinicians to challenge their counterproductive beliefs, and (3) training clinicians in specialized skills involved in shared decision making and patient-centered communication. More recently, Kissane et al²⁴ proposed a specialized communication skills curriculum for oncology that includes modules on breaking bad news, discussing prognosis and risk, facilitating transitions to family palliative care, discussing death and dying, and responding to emotions.

Limitations

Although the purpose of qualitative research is to gain in-depth (as opposed to broad) understanding of an experience, our relatively small sample size and our recruitment from academic medical centers limits our findings. Further research using mixed-method designs is needed to assess the generalizability of these findings in the oncology setting so that both depth and breadth of the phenomenon can be assessed. For example, our research pointed to several institutional factors that were named

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as barriers to effective communication, including the palliative care stigma, the lack of protocol, and the lack of tools and training for having these discussions. Further studies might assess how to ameliorate this stigma so that physicians would feel more comfortable having these conversations with patients. Wentlandt et al surveyed oncologists about referral practices to palliative care and found that one third of respondents would be more likely to refer to palliative care if it were renamed supportive care, indicating that there might be a stigma among clinical oncologists when it comes to referring to palliative care services. Addressing this stigma and increasing referrals to palliative care might be one important point of entry in assisting oncologists in having end-of-life conversations with patients and their families.²⁷ Other studies might examine how having an institutionalized protocol around end-of-life communication available may assist oncologists in discussing end-of-life care.

Conclusion

Given the ubiquity of death in oncology, open discussions and appropriate training and support for oncologists in this realm are essential. While there is heterogeneity among oncologists in their comfort with discussing end-of-life issues, a multipronged approach that involves support for the physicians, patient education, and institutional supports and allows for some customization is necessary.

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Author Contributions

Conception and design: Leeat Granek, Monika K. Krzyzanowska, Paolo Mazzotta

Financial support: Leeat Granek

Administrative support: Leeat Granek

Provision of study materials or patients: Monika K. Krzyzanowska, Richard Tozer, Paolo Mazzotta

Collection and assembly of data: All authors

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Leeat Granek, PhD, Department of Public Health, Ben Gurion University of the Negev, Be'er Sheva, P.O. Box 653, 84105, Israel; e-mail: Leeatg@gmail.com.

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Appendix

Table A1. Oncologists' Barriers to Communication About the End of Life

Theme	Subtheme	Supporting Quotations
Physician factors	Treating and palliation difficult	I'm bad at talking about death and dying with these people. [Because] I find that, as long as I have to treat them actively and focus on prolonging their life, talking about death and dying at the same time is really tough. I can think of patients where I really didn't do that well, where they really wanted me to support them morally and talk more about end-of-life issues, and palliative placement, and I was so focused on and so much in denial, you know, about that, that I didn't do a good job with that.
	Discomfort with death and dying	I think that if we don't do it [talk about end of life] it's because we'd rather not do it, because "A" we're uncomfortable, or "B" we don't think that the timing is right, or "C" all of the above or some mixture of that. It's almost like it's taboo in a way . . . No patients want you to say it, and that's the problem is that we often don't, we're not direct enough and we don't do a good job in end of life and dying, and it's almost like I'll laugh about some of the oncologists here who think their patients don't die.
	Team dynamics and responsibilities	Some of our staff are very bad at it and avoid it and don't come up to the floor and do it when they should. There's no doubt about that it's a problem. I'll give you a classic example: they ask me to see somebody stat one day and they said the patient is going to die within days and I said, "Is the patient DNR?," and the response was "No, but somebody should have that discussion." And I said "Well the somebody should be you because you're the doctor and you've known them for the last couple of years."
	The "death-defying" mode	The denial is that they're still doing 50 million tests, the patient's in a hospital dying, and they're still sending them for CTs and MRIs. Way too many tests . . . I see an inability sometimes to stop treatment when treatment should be stopped. . . . when treatment's futile, when it's clearly futile. I think it's an inability to sit down and have an honest discussion with a patient about what's coming. You'll see patients sometimes in the hospital . . . like sometimes we see it as a type of assault, the patients are in their last 24, 48 hours and they're still being poked, prodded, having all these things done to them that are completely medically futile. And not just medically futile but really putting the patients through discomfort.
	Lack of experience	It can be really difficult but once you get over it [discomfort discussing end of life], you actually do get a little bit used to giving bad news and things like that over time, as you do it over and over again and again.
	Lack of good mentorship	I just think you kind of learn to do it, and part of it is by watching your mentors. So . . . you're going in and you're seeing your supervisor deliver bad news, and depending on what the style is, you pick and model what you feel works for you and your personality.
Patient factors	Family's reluctance	You often struggle with it. There's some places where they [the family] don't even want to tell you you've got cancer, just give them chemotherapy. I cannot do that, they have to know what they're getting and why, and it has to be informed consent. So those are particularly challenging discussions. Now they may be angry with what you say . . . not as many patients but their family, that when you get to a point where there isn't anything else you can offer, and you say it's not right we really have to talk about how to transition into a palliative care setting. There are definitely times, where it's hardly ever the patient, it's almost always the family that's just very angry and won't consider stopping.
	Patient not ready	I think it's a bit of folie de deux or trois, or however many people are involved, because often when you see patients like this in a clinic, the patient does, you suspect, have some idea. That there's something horribly wrong. If you do have a patient that really doesn't want to know, and has either explicitly told you, you know, "talk to my son about prognosis or whatever," you'll do that.
	Language barriers	It may have been more of a communication blip, whether it's from their part or my part lost in translation. A lot of neo-Canadians that don't speak English as a first language or second language. Sometimes it can be difficult to try to explain, and they may not want you to say these words, in terms of there's no options.
	Younger patients	It becomes really tough and stressful . . . The system expects you to get them to that point. You're going to be criticized as an oncologist, honestly, if they get admitted to another service . . . "Does Dr. have blinders on? Can't he see that his patient's dying?" Yes I can see that the patient's dying. But you tell me, is it that easy to talk to a 20-year-old? And sit them down like you would [someone] who was 75? And say "you do you realize that you're dying within this time, we have to plan for all of this." It's not doable, and I get very upset at the other doctors they get admitted to [at] another service [who are] going to think that they're going to sit down and do that. They probably are a bit more vulnerable than somebody who's much more experienced in life and is 60 or 70 years of age versus someone who is 20. I'm probably just a bit more careful as to what I tell them, and I make sure their parents are there when I'm telling them so they have support. 'Cause a lot of them just don't know how to deal with the information.
Institutional factors	Palliative care stigma	That you know still for a lot of people palliative means last days . . . You'll hear doctors saying, "Oh yeah there goes [incomprehensible], the guys who kill my patients." That's how they put it. The problem is that a lot of patients don't want them [palliative care] involved because they see that as the death squad.
	Lack of protocol around end-of-life issues	You need to make referral to home care if your patient's at this level or to palliative care. There's no guidelines for any of that. That would be helpful. So people who struggle they'd have very clear guidelines about what they're to do and when they're to do it. That would be really helpful. That means that people will get referred to home care support, or palliative care or whatever when they need it.
	Lack of tools and/or training	It's actually a problem, because there are some people who just either don't feel comfortable or don't have the tools . . . and then, you have people who are at the end of their lives with respect to their disease, and they haven't really been told that. I think it's our job to bring it up. . . . Right? It's not [the patient's] job to talk about "Am I dying?" I mean they can ask that but to be afraid to approach it, I think we're afraid because we don't know how . . . You can't really do a good job and no one teaches you how to do it; but you're supposed to do it.

Abbreviations: CT, computed tomography; DNR, do not resuscitate; MRI, magnetic resonance imaging.