

# Dying From Cancer: Communication, Empathy, and the Clinical Imagination

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## Abstract

Medical oncologists and patients with advanced cancer struggle to discuss prognosis, goals, options, and values in a timely fashion. As a consequence, many patients die receiving aggressive treatment potentially inconsistent with their fully informed preferences and experience increased symptom burden and distress. The goals of patient - oncologist communication include exchanging information, building relationship, and engaging in shared decisions. Empathy is perhaps especially essential to effective patient - oncologist communication when the end of life is approaching. We speculate that, in addition to being a skilled response to a patient's negative emotions, empathy is an emergent property of the relationship that allows the patient and oncologist to imagine what it will be like to navigate the transition from living with to dying from cancer; and to prepare for the transition. We propose that effective empathy: 1) requires an attentive, curious and imaginative physician; 2) acknowledges the complex and shifting goals as the end of life approaches; and 3) begins with a willingness of physicians to check in and find out what she may have misunderstood or misperceived. Empathy in end of life conversations cultivates the shared experiences necessary to co-create the new goals of care that underlie excellent end of life care.

## Keywords

empathy, cancer, end of life, decision making

“...[W]hat we have ultimately as our guide is whatever understanding we may have gained along the way of ourselves and others...From here on, then, in the blinding smoke it is no longer a “seeing world” but a “feeling world.”

N. Maclean  
Young Men and a Fire

## Introduction

More than 600 000 Americans die of cancer each year. Their final experiences with cancer may be described by what happens before, during, and after the transition from living with and, often, being treated (see note 1) for advanced stage, incurable cancer to being cared for while dying. Patients and their oncologists often struggle to find common ground and to engage in meaningful conversations about when, how, and why to transition to end-of-life (EOL) care. As a consequence, many people who die from cancer experience unnecessary distress, and there is uncertainty about whether they have made informed decisions consistent with their values and goals for the end of their lives and beyond. The purpose of this contribution to The Journal of Patient Experience is to

propose that, in addition to skilled responses to patients' negative emotions, empathy is an emergent property of the oncologist-patient relationship that allows them to jointly modify expectations—such as an improved life expectancy with further chemotherapy—and imagine a future consistent with dying well. We will briefly summarize salient observations about the EOL experience of people with advanced cancer and how communication with oncologists influences them, then turn to a specific focus on empathy.

## Dying From Cancer

Americans who die from cancer often receive overly aggressive, *predictably* futile medical treatments toward the EOL and, as a consequence, die poorly. Conversely, patients who

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die while receiving hospice care—one type of purposeful EOL care—die better deaths. Regional variations in rates of aggressive treatments or hospice enrollment, the unrealistic expectations of people with advanced cancer about their life expectancy or goals of treatment, and the reluctance of oncologists to discuss poor prognoses or options for EOL care (1) suggest advanced cancer patients' EOL decisions are not always fully informed (2,3). To address these gaps, innovative ways to improve communication and patient understanding about prognosis and improve decision-making are urgently needed.

Three observations, however, suggest that the dynamic described in the preceding paragraph is overly simplified: (a) Analyses of patterns of treatment over time demonstrate that advanced cancer patients are both more likely to receive aggressive treatments and hospice care than in the past (4,5); (b) qualitative studies demonstrate that patients may choose chemotherapy near the EOL as a means to “live in the moment” rather than due to misunderstanding the goals of treatment (6); and (c) patient preferences for prolongation of life may explain the continuation of aggressive EOL treatments (7,8). Whatever the case may be, however, alignment of the goals and values of a fully informed patient with the treatment or care received at the EOL remains a fundamental fiduciary responsibility of the physician. And communication about the best care as life is ending requires excellent communication skills.

## Communication

Patient–oncologist communication matters. Cross-sectional studies of patients with advanced cancer near the EOL have demonstrated that patients who accurately recall information, presumably from conversations with their oncologists or others about prognosis or EOL care options, choose different EOL treatments or care than people who don't and experience a better EOL (9,10). Unfortunately, most patients with advanced cancer report overly optimistic impressions of their life expectancy and/or the goals of treatment (11,12). These impressions seem to lead to more aggressive treatments and adverse outcomes near the EOL.

Let's assume for a moment that increasing the *accuracy of the patient's impressions* is necessary to improving the quality of the EOL experiences of advanced cancer patients. For the oncologist, the challenge is one of identifying the communication behaviors that increase recall of the *kind of information* that is most salient to the transition from curative to palliative care and from palliative care to EOL care, *in a way* that is consistent with patients' preferences and the *actions (EOL care) needed to realize them*. Communication between patients and their oncologists serves multiple purposes including establishing a good interpersonal relationship, facilitating information exchange, and involving patients in decision-making (13). From a communication perspective, the evidence to date suggests that oncologists can definitely can improve the quality of information

exchange and adopt more inclusive decision-making behaviors. Patients' impressions, however, are influenced by more than patient–oncologist communication: (a) Patients learn from other patients and informal networks, like family and friends, what is likely to happen (14); (b) patients may independently report more favorable prognosis as a means of expressing optimism, their uniqueness, or skepticism about the prognostic accuracy of physicians (15); and (c) patients rely on more intangible qualities like hope, than information, as the likelihood of benefit from chemotherapy diminishes over time and multiple treatments (16). These factors are potentially independent of patient–oncologist communication; however, they can become part of the conversation when asked about and explored as a meaningful part of the relationship (17).

## Empathy

We begin our discussion of the ways in which empathy may be essential to conversations about EOL by proposing that empathy may be understood as a capacity or a set of behaviors. Hojat and colleagues have demonstrated that a pathway between cognitive empathy (a measure of empathic capacity) and changed health-care behaviors exists. The investigators found correlations between higher levels of self-reported physician empathy and improved outcomes in patients with diabetes in the United States (18) and Italy (19). The actual mechanism(s) that link physician capacity or intentions with patient behaviors remain unclear. Presumably, the path includes the behaviors the physician exhibits, the patient perceptions and interpretation of the behaviors, and the actions the patient takes based upon her perceptions and interpretations.

The second way to understand empathy is as recognizable communication behaviors. It seems likely that oncologists' capacity for empathy is actualized through patient perceptions of them. One widely studied behavior is recognizing and responding to patient's expression of negative emotions conceptualized as empathic opportunities (20,21). What do patients perceive when physicians *behave* with greater empathy? Tulskey and colleagues (22) reported the results of a randomized trial of a computer-based training program to enhance oncologists' responses to patients' expression of strong negative emotions. The study randomized 48 oncologists to either a 1-hour lecture or a 1-hour lecture and a CD-ROM training program on communication skills with examples from audiotapes of actual encounters with patients. Subsequently, encounters between all oncologists and 264 enrolled patients with advanced cancer were audiotaped and analyzed. In addition, patients were surveyed approximately 1 week after the encounter. Oncologists in the intervention group were twice as likely to use empathic statements or use continuers (verbal or nonverbal cues that encourage further elaboration of the topic or emotion being expressed) in response to an empathic opportunity (rate ratio: 1.7,  $P = .024$ ; odds ratio: 2.1,  $P = .028$ ). The patients' perceptions

of the encounters, however, were essentially the same between control and intervention oncologists although there were slightly higher scores on trust. The perceived empathy scale scores were identical.

There are two potentially relevant interpretations of the above findings. The first is that the instrument used to measure patient perception of empathy (consultation and relational empathy [CARE]) was insensitive to the specific behaviors fostered by the curriculum. Higher scores on CARE, however, have been correlated with patient enablement and reduction in the duration of the common cold (23,24). If CARE is insensitive to clinician responses to empathic opportunities, then the question of what patients respond to is an open question. This raises the second interpretation: oncologists' responses to negative emotions are only one of many potential influences on the patient's perception of the interaction. Two studies support the idea that patients' perceptions of communication about emotions differ from physicians. Fagerlind and colleagues (25) demonstrated that physicians reported discussions of emotional functioning more often than was reported by patients or observers. The physicians and observers, however, agreed on quality of overall communication. Perhaps more problematic are the observations of Salmon and colleagues that breast cancer patients and their surgeons describe their relationships as emotional and personal but observers coded no instances of emotional exchange (26). The quality of the relationship seemed to depend on the surgeon's expertise and the actions that affirmed their expertise in the patients' mind. Thus, while attending to emotions may be of value for a particular patient, it seems neither necessary nor sufficient.

## Reflections

Much of the literature on empathy focuses on the capacity to feel or resonate with a patient's distress. In this framework, empathy is treated as a property of the individual who has it in greater or lesser amounts. The other common framework treats empathy as a range of communication behaviors which the individual exhibits to a greater or lesser degree. There is abundant evidence that suggests either type of empathy is linked to patient outcomes, although the direction and mechanisms of the interaction have not been elucidated (27). Conceptualizing empathy as a capacity or a behavior of an individual, however, misses, in our mind, the more likely possibility that empathy emerges during the interactions between oncologists and patients. We offer 3 reflections on how to foster the emergence of empathy during these interactions.

### *Empathic Communication Requires an Attentive and Imaginative Physician*

An essay entitled, "The Patient Examines the Doctor" by the cultural critic Anatole Broyard in his book *Intoxicated by My Illness* (1992), described the kind of physician he wanted

when he was diagnosed with metastatic prostate cancer. His ideal physician ("medical man") would be "a close reader of illness and a good critic of medicine"; "a bit of a metaphysician . . . someone who can treat body and soul"; and someone who has read "a little poetry as part of their training." His ideal doctor is thus equipped to, ". . . scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness." We agree with the idea that oncologists need to be trained to be more aware of emotions, and we suggest that they may often have to be imaginative in understanding what their patients are experiencing in their journey with cancer. It seems to us that the doctor not only recognizes what is said but offers a way for the patient to say what she or he is struggling to find the words for.

### *Empathy Occurs Within a Complicated Communication Environment With Shifting Goals as Life Ends*

Patients, family members, and oncologists enter conversations with needs, beliefs, values, emotions, and goals that influence what is said, what is recalled (28), and what sort of relationship is established. The task of helping patients takes those uncertain steps from being a person with a life-limiting disease to a person who is dying is not for the faint of heart (29). The oncologist—who is first consulted for his expertise in *treating cancer*—must offer herself in a different way to form the relationship necessary to care for the dying person. So the idea that a goal of oncologist–patient communication is to foster a good relationship takes on new meaning. The relationship evolves to a more human connection when expertise in treating cancer is less germane to the patient's future. Empathy becomes more of a bond. To quote Broyard:

I wouldn't demand a lot of my doctor's time: I just wish he would *brood* on my situation for perhaps five minutes, that he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.

This leads to our final reflection.

### *Accurate Empathy Is the Key to Effective Empathic Communication*

There are times—when we are in a smoke-filled world and the sight we typically depend on is unreliable—when we move with our hands out in front. We touch, form judgments, test their soundness, and move forward, not with certainty of ending well, but with some sense that our method is sound. Empathy is an essential skill and it is also a skill that requires humility, the willingness to check in and to find that we were accurate or wrong in what we perceive, and the confidence to admit that we were wrong or premature in our judgment. We should not regret our errors. Inaccurate or misplaced

empathy creates an opportunity for course correction, adaptation, and in some cases apology, all of which are pathways to greater intimacy and trust (30,31). Our goal is to make sure what should emerge from the conversation does.

Empathic accuracy is not based on an individual's capacity for empathy but rather on what emerges from the interaction. Empathic communication is a property of the dyad; not the individual, this difference creates an entirely different frame in which to view empathy. The steps to achieve empathic accuracy have been described elsewhere and can be summarized, in their simplest form, in 4 steps:

1. Recognizing emotions: The oncologist's ability to "read" patient expressions of emotion. These can be linguistic, for example, the use of words that have or imply positive or negative emotion and/or nonverbal, for example, cues such as facial expression, body posture, and eye gaze.
2. Sorting: Drawing inferences and assigning meaning to the stream and structure of behavior as it emerges in interaction. Both accuracy and inaccuracy are based on making inferences about one's observations.
3. Responding: Enacting a response based on one's inferences that is designed to respond to the particulars of interaction, the recipient, and local context.
4. Attentive listening: As an emergent property of the interaction, assessing accuracy depends upon listening and acting upon the response it produces in the patient.

Accuracy in empathic communication creates powerful bonds between the oncologist, patient, and family that are apparent in the trust, mutual respect, and the acknowledged sadness that life is ending. These bonds allow the person dying from cancer to imagine—with his oncologist—the course of action that leads to comfort and dignity of care rather than the distress of continued and futile treatment. The eminent physician, Sir William Osler, is credited with having said to his trainees on multiple occasions, "Listen to your patient, he (or she) is telling you the diagnosis." Although we presume in his era he was talking about disease and biomedical diagnoses, we believe the aphorism applies in equal measure to the accuracy of empathic communication between oncologists and their dying patients.

In summary, we believe empathy is part of a larger project of being human and the desire on the part of 1 person to ease the suffering of another human being who may be frightened, unable to process information, and unable to articulate their needs and desires in a coherent way.

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### Notes

1. We will use the word "treat" and its derivatives to connote interventions targeted either at treating the cancer such as chemotherapy or at sustaining life such as resuscitation. The word "care" will connote interventions targeted toward the whole person with the intention of alleviating physical symptoms or psychological and existential distress. There is overlap. The adjective palliative is used before chemotherapy at times to communicate the goal of chemotherapy is not curative and to raise the possibility that chemotherapy may relieve symptoms through shrinking the cancer.

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