Guilt and the Burden on Oncology Providers

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I still remember when I professed my intention to become an oncologist while in residency. Some of my colleagues were supportive, but others were openly disdainful: “What a terrible field—all death and dying, and all that false hope.” I remember the thought that went through my mind at that time, too. It was an Emily Dickinson poem:

Hope is the thing with feathers
That perches in the soul,
And sings the tune—without the words,
And never stops at all . . .

Oncology is a field in continual evolution. Although once our best treatments involved hormone manipulations and mutilating surgery, we now are well on the path toward precision medicine. This is the hope of clinicians in our field—better treatments, less toxicity, more individualization—treatment that can cure this devastating disease and, short of that, turn it from life-threatening to chronic. Death is not a “given” in our clinics and inpatient units anymore. Most of our patients are not dying of cancer; they are living with cancer.

Despite our hope and advancements in treatment, the reality is that not all of our patients will live through cancer, walk through treatment without side effects, or hear the word “remission” based on the latest imaging test. Some of our patients will die of their cancers. As often as we greet new patients and embrace patients we have known over a longer period of time, we will say (and have said) good-bye to many others.

When a patient dies of cancer, hope can be replaced with questions. Could we have done something more? Should we have done something different? Would I make the same recommendations if I could counsel him (or her) all over again? Hope can transform into something altogether different, like the sun clouding over and its yellow yielding to graying skies. Some would call it guilt, but I think it is more than that. I think this quote attributed to the preacher Horace Bushnell was more correct when he said,

“Guilt is the very nerve of sorrow.” I have come to realize that perhaps “guilt” is really sadness.

In this issue of *The Oncologist*, three extraordinary experiences of patient care are presented, and each represents a strong narrative of that emotional and sensitive part of our jobs centering around the end of life and, ultimately, the death of a patient. They are shared as recollections of individuals, as in the cases of Drs. Halmos [1] and O’Reilly [2], and of the team experience recalled during Schwartz Rounds at Massachusetts General Hospital [3]. Each demonstrates that we are not immune to our patients’ end-of-life experiences. We are a part of that, and we should acknowledge how hard it can be.

Dr. Halmos is at the movies with his kids when the experience is interrupted by news of a patient’s sudden turn, ICU stay, and quick death [1]. The interruption is irreversible, and his attention is split now. On the one hand, he is a father with his children out at a family event; on the other, he is a doctor with responsibilities to his patient, recalling conversations had, treatments tried, and the stark realization that his patient is at “the end of the road.”

Dr. O’Reilly shares his experience from a place two steps removed from that of Dr. Halmos [2]. He recalls the death of a patient and a letter received posthumously, written months before and meant to be read after the patient had died. The letter was one of thanks: “Thanks for trying, thanks for hoping, and thanks to your family for their sacrifice.” No reply is expected, no confirmation of receipt necessary. Indeed, this patient is now deceased, and as Dr. O’Reilly notes quite starkly, “Any inadequate reply that I could compose will never be read. It can’t be.”

Dr. Schapira et al. tackle the real-time experience of caring for a person who is not only at the end of the cancer journey but who is also a colleague [3]. Boundary issues are explored, including the challenges of being a patient at an institution where the patient was also a provider, the desires of family and the wishes of

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the patient, the relationships built on collegiality and now challenged by illness. It is a story of empathy, sorrow, and support—the inpatient team experience of dying and death.

One might wonder what the consequences of these experiences are. There are no words of wisdom regarding the “appropriate” way to respond to these situations, and I do not think there will ever be a definitive response. Just as each patient’s journey after cancer is individual, perhaps each practitioner’s approach to end of life is also personal. It is my hope that these narratives stimulate the reader to ask himself or herself, “How would I respond?”

For me, I have learned that I cannot go to the funerals of patients. It hurts too much, and I am not ashamed to admit that. Instead, I have made it a point to say good-bye to patients at the end of their lives, when I feel their time has come and it is likely that I will not see them again: “It has been the greatest honor to know you and to be with you during your cancer. You have taught me how to care, and I will not forget you.” Looking someone in their eyes, acknowledging the moment, and saying good-bye has provided for me the best coping mechanism—closure.

These narratives in medicine reflect the human experience of oncology. They remind us that we are not alone in feeling guilt,

pain, and even sorrow when our patients die. Indeed, the reader may see himself or herself in these stories or recall another personal experience. And perhaps that it is the bigger point: to emphasize the art of oncology, the humanism in medicine, and to remind us that we are not superhuman and we are not gods. Our patients’ end-of-life experiences are part of the journey that we, as their oncologists, embarked on with them at the beginning. Whether or not we are able to be present with each patient at the time of his or her death, it remains a powerful experience for those of us on the clinical side of the therapeutic relationship. Beyond biology and targeted therapy, we are equally as human as our patients. When it comes to the end-of-life journey, as clinicians, we must feel it, experience it, and acknowledge it.

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EDITOR’S NOTE: See the articles referenced in this commentary on pages 545–549, 574–575, and 576 of this issue.