

# Yes, I can

Learning to cope with death

**YunZu Michele Wang, MD**

The author is an intern in Pediatrics at the University of California at San Diego. This essay won third prize in the 2013 Helen H. Glaser Student Essay Competition.

**B**ut it's so sad!" Every time I mention that I am interested in pediatric hematology/oncology, this is what I hear. Sparked by an undergraduate research experience

investigating the pathways involved in hematopoietic stem cell emergence, I became fascinated by the concept of bone marrow transplantation. But before committing myself to a career in pediatric hematology/oncology, I wanted to deal with my lingering fear of being unable to cope with death.

In the foreword of Bernice Harper's *Death: The Coping Mechanism of the Health Professional*, Dr. Jesse Steinfeld writes that many health professionals "unfortunately will contribute to their patient's anxiety" because they are "unable to cope with [their] own discomfort about death."<sup>1p vii</sup> I was afraid I would be one of them.

The seminal *On Death and Dying* by Elizabeth Kübler-Ross helped me understand why I was so uncomfortable with death. In our society,

children are excluded [from coping with death] with the presumption and pretext that it would be "too much" for them . . . we ship the children off to protect them from the anxiety and turmoil.<sup>2p6-7</sup>

I was one of those children. Relatives who passed away did so on an island 6700 miles away. I did not attend a funeral until college.

My first experience witnessing the death of a stranger was during a premedical shadowing program. A young man was brought in after committing suicide by jumping off a building. My memories of the exact series of events are hazy; I was too excited, too scared, too horrified. Throughout the entire resuscitation, I kept thinking, "He's too young to die," and simultaneously, "But he wanted to die. We're trying to give life back to someone who no longer wanted it." Finally, the code was called, and as our team trudged back to



*Denial*

our floor, a third-year medical student turned back to me and asked if I was okay. It was her second experience with death, she admitted, and no less difficult than her first time. "I'm okay," I assured her. My muscles, each and every one tense in the ED, gradually relaxed. I was walking and talking, my heart was still beating, my vision still clear—physiologically, I was okay. Mentally, though, I was still dazed. We returned to rounds, and the topic was not brought up again.

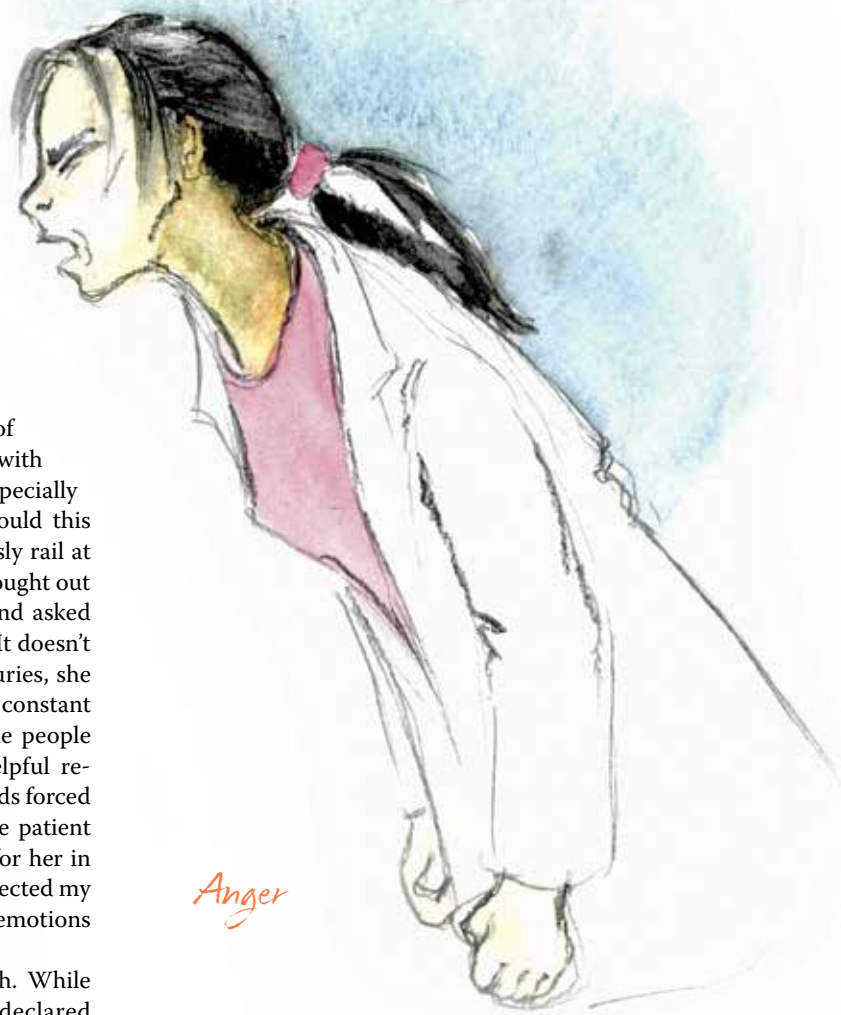
More recently, during my third year of medical school, I was part of the surgical team responding to a pediatric trauma event. I felt the same flood of emotions, the same tightening of my entire body, but with more anger. There was more I could not process, especially the nagging "Why?" and the unanswerable "How could this happen?"—unhelpful questions that made me uselessly rail at the world and its injustice. Before I left for the day, I sought out the pediatric trauma nurse who had been with us and asked her how she could deal with seeing cases every day. "It doesn't ever get easier," she told me, "but given all of her injuries, she is in a better place now." For her, the cases were also a constant reminder to value the relationships she had with the people around her. This was the most satisfying, most helpful response I could have received at that moment. Her words forced me to accept that what had already happened to the patient had happened and that what could have been done for her in the emergency department had been done. They redirected my attention from my own mountain of unmanageable emotions to the patient—and left me at peace.

Those were my experiences with traumatic death. While situations in the emergency department quickly declared themselves as black or white, oncology has all shades of gray. How do health professionals face patients and their families every day with the uncertainty they carry? How do they bear this emotional weight?

I spent a month reading the literature on coping with death and end-of-life care, hoping to resolve my own nagging fears about death. I hope that what I learned will work for me in the future, and I am sure more experience will help me develop coping strategies. For now, I believe that a foundation of clear and honest communication with our patients, particularly about death, allows us to concentrate on realistic goals for both ourselves and them. While doing this, we must also be mindful of our own reactions and practice self-care.

When caring for patients, communication is key. Kübler-Ross emphasizes the need to communicate early and often in the course of the illness. She highlights the importance of interpreting body language, noting that caretakers often focus

on the equipment rather than on the facial expressions of the patient, which can tell us more important things than the most efficient machine.<sup>2p18</sup>



While there were certainly times when variations in the blips and beeps of the monitors caused momentary panic, I learned that more reliable indicators of how kids felt were their crossed arms or their pouting lips. Likewise, when my stethoscope on bare skin caused a grimace, I knew it was not the time to wean pain medication. By watching and listening, we give the patient a voice in the direction of care.

To Cicely Saunders, founder of the palliative care movement, it was important to have someone, such as the bedside nurse, there

to explain what a doctor had said and to listen endlessly to fears . . . [since] so many crippling emotions are less powerful to hurt once they have been expressed to another person.<sup>3</sup>

As the third-year medical student, officially the lowest ranking (and in my case also shortest) member of the team, I considered myself the least intimidating person. As the one



## Bargaining

with the most time, I felt that I spent the most time with my patients and that that time, together with my approachability, made it obvious to me that I should be their confidante. But as much time as I thought I spent with them, I quickly realized that their nurses spent more. More times than I can remember, nurses raised concerns that parents or patients were hesitant to bring to the attention of the medical team.

When death is possible or probable, it must be addressed. As Kübler-Ross puts it, death is often “a frightening, horrible, taboo topic,”<sup>2p28</sup> our real-life Voldemort. To the superstitious, and sometimes even the usually-nonsuperstitious, talking about death will cause it to happen. That fear seizes our hearts and evicts reason. We do not need to talk about death in every conversation with the family; we do not need to bludgeon it into them until they accept. But we must be open to discussion and brave enough to initiate that first discussion, and afterwards, continue our support of the patient and family throughout the entire process. To the uncomfortable question of “Should a patient know . . . ?” Saunders argues that the answer is, undoubtedly, yes. It is our duty to patients—“If they do

ask I believe they should be told.” She does advocate for some degree of knowing and understanding the patient first, since sometimes “we judge the patient to be unready as yet to face the full knowledge. But then we must return, for this may need a whole series of exchanges.”<sup>4</sup> Avoiding the topic of death will not prepare the patient for this news; rather, honest communication and unhurried exploration of his or her understanding of the condition and beliefs about death are excellent starting points. If and when patients reach the final Kübler-Ross stage of acceptance,

the family needs usually more help, understanding, and support than the patient himself. While the dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of the outside world.<sup>2p100</sup>

And after death, especially for pediatric death, our role is not silence. It is, in the words of Joan Arnold and Penelope Gamma,

To listen and to speak of child death, recognizing it for all that it is—an unparalleled human tragedy. To ensure that families will be respected and admired for their ability to deal with the vastness of their loss, we need to legitimize their loss, to talk openly about the dead child. To continue the silence is somehow to deny the child’s very existence.<sup>5p130</sup>

Several resources are available to help us find just the right words, especially in difficult situations with their own nuances, such as death in the delivery room and in the ED.<sup>6</sup> For both health professionals and parents, the United Kingdom’s Child Bereavement Trust website ([www.childbereavement.org.uk](http://www.childbereavement.org.uk)) specifically addresses what to say to the bereaved about the death of a child. Although a few choice words may suffice to start that difficult discussion, one may also turn to those who are experienced to learn how to sustain such a conversation. In *The Anatomy of Hope*, Dr. Jerome Groopman writes that

learning how to care for patients was still very much like being an apprentice in a medieval guild. You closely and repeatedly observed master craftsmen at their work and then, largely on your own, tried your hand at it.<sup>7p32</sup>

I have always learned by modeling my teachers, whether it was crossing out units in dimensional analysis or using a suction pipette. But opportunities to observe my medical school teachers engaging in serious discussions with their patients were neither open nor plentiful. Our Practice of Medicine course supplemented discussions about the art of medicine with role-playing sessions, but all of the role-playing sessions in the world could not reassure me that I would be competent in the delivery of bad news. As an MS3 and MS4 I seized every opportunity to go



with my team to any serious discussions. Unlike the traditional see one, do one, teach one, I knew I needed more than one experience, and even now, I know I need to observe more master clinicians at their compassionate best. With their guidance, and most importantly, with more practice of my own fledgling skills, I hope to develop a level of mastery in the art of delivering and discussing bad news that will allow me to be a source of comfort to patients and families in distress.

One communication pitfall I have been guilty of is that of telling patients and their families only what they want to hear. I am an inherently optimistic person, but as the bearer of news and the interpreter of test results, I felt pressure to set a good



#### About YunZu Michele Wang, MD

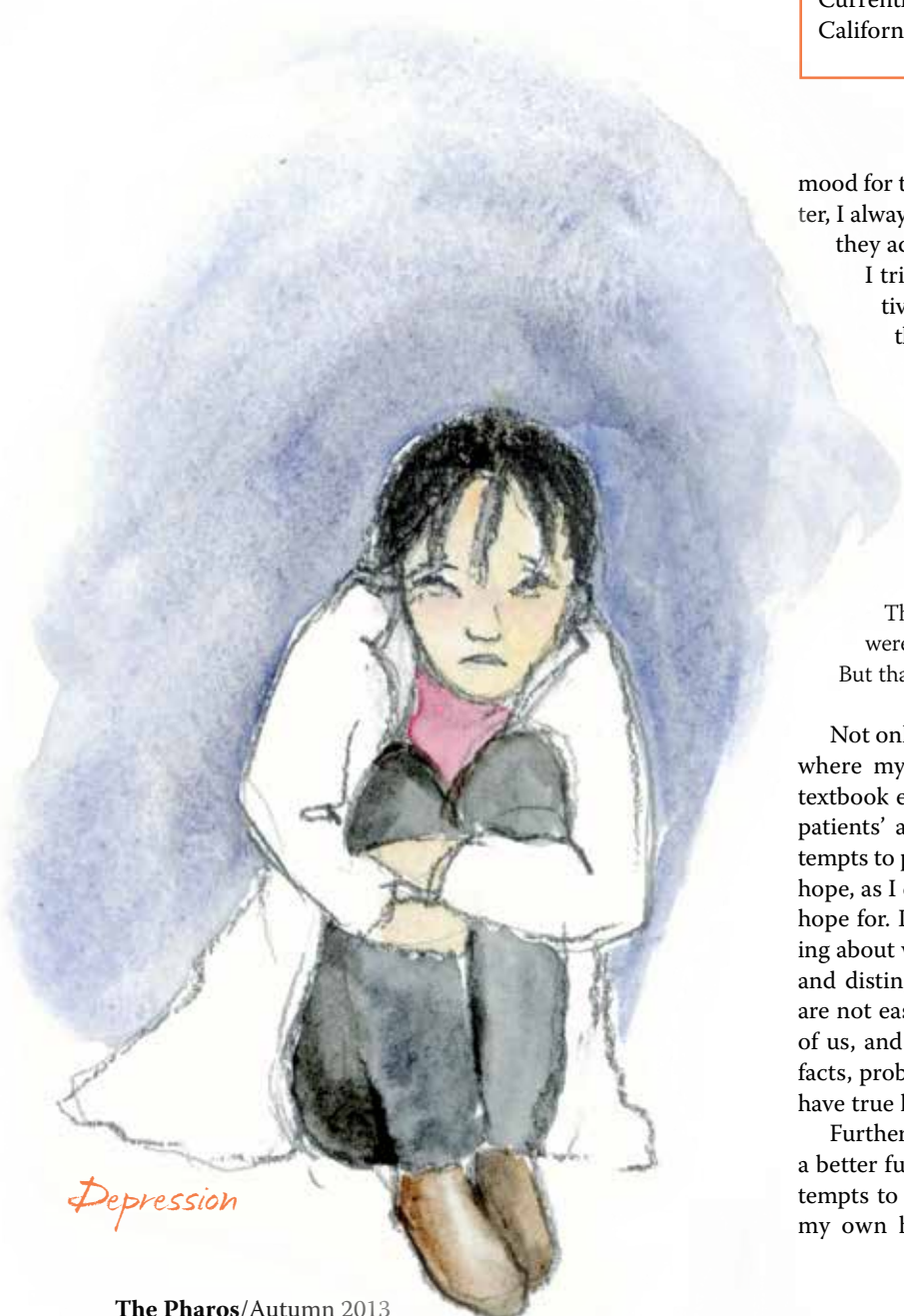
I grew up in Arcadia, California, reading all the time. I continued to do so while obtaining my degree in biochemistry at UCLA, albeit less for personal enjoyment and more to pass my classes. My childhood was full of the outdoors, bargain shopping, delicious Taiwanese food, and my parents' emphasis on the value of education. I am incredibly grateful for the support of my family, friends, and all of my twenty-one years of teachers from the Arcadia Unified School District, UCLA, and Washington University School of Medicine. Currently, I am a Pediatrics intern at the University of California in San Diego.

mood for the day. Knowing that both content and delivery matter, I always tried to emphasize the good things or the progress they achieved. Even if it was not what they wanted to hear, I tried to balance unwanted news with something positive. But when I was asked a tough question or when the answer was bleaker than having to stay in the hospital for a few extra days, I faltered. Unable to depict the situation positively, and still inept at delivering bad news, I dodged the question and desperately emphasized the few things that were going well. Unconsciously, I was probably in the Kübler-Ross stage of denial; I wanted to protect the family from my own despair. As Groopman tellingly describes it,

The evasions, the elliptical answers, the parsed phrases were all supposed to be in the service of sustaining hope. But that hope was hollow.<sup>7p53</sup>

Not only was I starting down a slippery slope of half-truths, where my integrity could be questioned, but I was also a textbook example of a health professional contributing to her patients' anxiety by avoiding their questions. Worse, my attempts to protect the family were also weakening their basis for hope, as I denied them the knowledge of what they could even hope for. Laying out the risks and benefits of treatment, talking about what a sixty percent chance of survival really means, and distinguishing between curative and palliative treatment are not easy. But this is what patients have the right to expect of us, and what we must do. Only with understanding of the facts, probabilities, and options available to them can patients have true hope.

Furthermore, for patients to believe that there is a way to a better future, the medical team must have hope, too. My attempts to dodge the patient's and family's questions betrayed my own hopelessness, and they probably saw through it.



According to Harper, “To consider a disease or patient hopeless is often to render them so,”<sup>1p18</sup> which Groopman reiterates: “for a physician to effectively impart real hope, he has to believe in it himself.”<sup>7p209</sup>

This is more than the so-called power of positive thinking. Neither physician nor—especially—patient may consider alternatives or take risks if they feel that nothing will make any difference. Our only option is to use our knowledge and experience to guide our patients. Groopman relates the thoughts of Richard Davidson, PhD, Director of the Laboratory for Affective Neuroscience at the University of Wisconsin,

Hope does not cast a veil over perception and thought. In this way, it is different from blind optimism: It brings reality into sharp focus. In the setting of illness, hope helps us weigh highly charged and often frightening information about the malady and its therapies. Hope incorporates fear into the process of rational deliberation and tempers it so we can think and choose without panic.<sup>7p199</sup>

How do I find hope in seemingly hopeless situations? By reframing—looking beyond the ominous circumstances to see that there is much I can do for the patient in front of me. By ceasing my own useless and unsatisfying “why?” questions and, above all, by making it about my patients and not about me.

Unconsciously, or perhaps sometimes deliberately, as August M. Kasper writes,

The dying are thus not neglected, but they are very rarely approached with hope or even interest, because, I suppose, they simply will not feed the doctor’s narcissism by responding and getting well. Their care is demanding, frustrating, and far from helpful to the medical magician’s self-esteem.<sup>8p5-6</sup>

Things do not feel so awful when we focus on our patients instead of ourselves, and give instead of looking to gain.

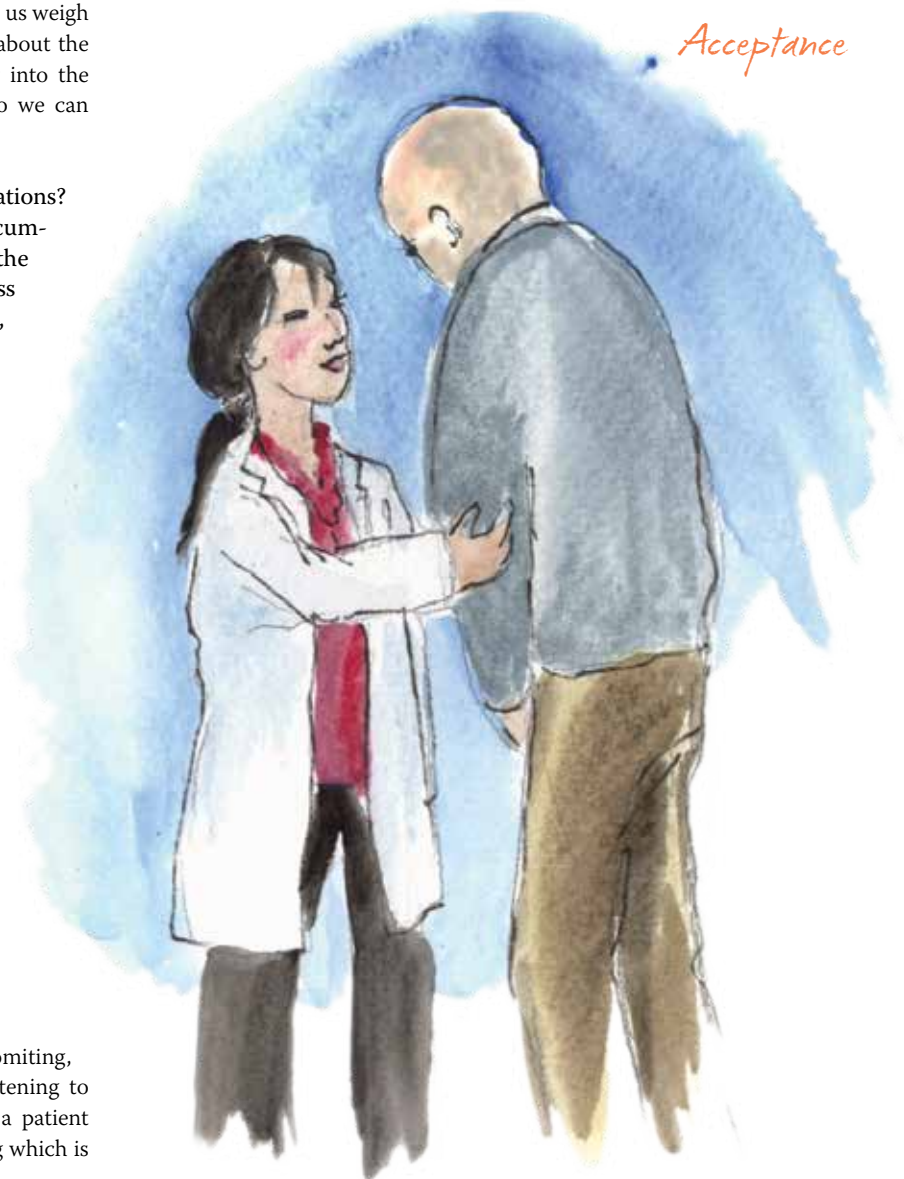
The advice I received following my own experience in pediatric trauma exemplified such an attitude. It was a reminder to focus on doing what I could for the patient, instead of allowing myself to be overwhelmed by my negative emotions. With her experience as both a nurse and physician, Saunder stresses that

Much can be done to control pain, nausea and vomiting, to relieve dyspnoea and confusion, both so frightening to any patient. Skill at this stage helps us come to a patient with ever renewed interest and that positive feeling which is

transferred without words. It can do so much to lift the feeling of helplessness from a patient as well as from ourselves.<sup>3</sup>

As a medical student, the opportunity to do something, anything, to be helpful—as opposed to hopelessly helpless—was especially significant in emergency situations. I can imagine that the satisfaction of being able to medically manage and ease a patient’s long-term suffering and death must be magnified manifold.

In addition to reframing our own mindsets, helping the patient and family reframe theirs may bring further satisfaction. Instead of hope as a single entity, “alluring but vague,



revered but ineffable, aloof from daily life and mostly inactionable,” identifying “smaller, salient, and steadying” hopes brings to light more achievable, and perhaps more meaningful, goals.<sup>9</sup> Recognizing “hope as a force that helps to carry the unbearable,” patients can be asked about their “hopes for the future and the good things that inspired [them] to continue to live.”<sup>10</sup> In the same way that we need to refocus our attention on matters within our control, we should also help our patients acquire some measure of control over their own conditions.

Beyond doing the best for our patients in the hospital or office, we also need to deal with our thoughts and emotions. Burnout and compassion fatigue are common in physicians caring for patients with end-stage illness; they need not be inevitable, however, as several self-care and self-awareness methods to prevent burnout can help.<sup>11</sup> A very delicate balance in the physician-patient relationship needs to be maintained. As oncologist Dr. David Steensma writes,

If I get too close to my patients and allow myself to become emotionally entangled in their suffering, every death feels like the loss of a family member. I risk becoming paralyzed in grief. But if I don't allow my patients' agony to hurt me at all—if I attempt to preserve myself by making myself untouchable, emotional Gore-Tex—then, like old Tithonus, who was granted immortality but not eternal youth, I am condemned to shrivel up into a grasshopper, abandoned by the voice needed to give comfort to my patients.<sup>12</sup>

Recognizing risk factors related to closeness of the physician-patient relationship may help one avoid both compromising clinical judgment and physician burnout.<sup>13</sup>

In addition to self-awareness, a supportive environment at work is championed in almost every work I have read. It is a very special bond formed by shared experience. Already, in my brief years of clinical experience, residents, nurses, and attendings have provided the necessary “listening ear with simple support and encouragement,”<sup>14</sup> and I know I will value their help even more in my future. While studies show that an official debriefing following a traumatic event carries both risks and benefits,<sup>15,16</sup> I believe that the health professionals involved in such an event should not be expected to mute their grief any more than the family should.

I know this is not the end of my learning. I wanted a how-to guide, an instruction manual, but this is not that kind of experience. I wanted to cross off “confront fear of death” from my to-do list, and then run away and get as far as I could from it until having to confront it again. What I have learned, however, is that it is really not so fearsome. Developing the courage and confidence to approach patients about the possibility of their deaths will certainly take more observation and experience, just as it will take more experience to learn to manage the clinical aspects of end-of-life care. But understanding our patients’

views and goals and what we can help them achieve will give us hope. And practicing consistent self-care and promoting a supportive work environment will allow us to endure and carry on.

Death, and pediatric death in particular, is a terrible tragedy but as one social worker put it, “I cannot stop that, or make it go away by running away from it, so I must turn around and help.”<sup>1p60</sup> And so I will.

#### Acknowledgments

Thanks to Dr. Elliot Gellman and Elaine Khoong for editing, and to Mary Alice McCubbins, PNP, for inspiration.

#### References

1. Harper BC. *Death: The Coping Mechanism of the Health Professional*. Greenville (SC): Southeastern University Press; 1977.
2. Kübler-Ross E. *On Death and Dying*. London: MacMillan; 1969.
3. Saunders C. The management of fatal illness in childhood. *Proc R Soc Med* 1969; 62: 550–53.
4. Saunders C. Care of the dying—3. Should a patient know...? *Nursing Times* 1976; 72: 1089–91.
5. Arnold JH, Gemma PB. *A Child Dies: A Portrait of Family Grief*. Rockville (MD): Aspen Systems Corporation; 1983.
6. Levetown M. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008; 121: e1441–60.
7. Groopman JE. *The Anatomy of Hope: How People Prevail in the Face of Illness*. New York: Random House; 2005.
8. Kaspar A. *The Doctor and Death*. In: *The Meaning of Death*. New York: McGraw-Hill; 1959: 259–70.
9. Feudtner C. The breadth of hopes. *N Engl J Med* 2009; 361: 2306–07.
10. van Laarhoven HWM, Leget CJW, van der Graaf WTA. When hope is all there is left. *Oncologist* 2011; 16: 914–16.
11. Kearney MK, Weininger RB, Vachon ML, et al. Self-care of physicians caring for patients at the end of life: “Being connected . . . a key to my survival.” *JAMA* 2009 Mar 18; 301: 1155–64.
12. Steensma DP. The narrow path. *J Clin Oncol* 2001; 19: 2102–05.
13. Wolpin BM, Chabner BA, Lynch TJ Jr, Penson RT. Learning to cope: how far is too close? *Oncologist* 2005; 10: 449–56.
14. Reynolds F. How doctors cope with death. *Arch Dis Child* 2006; 91: 727.
15. Baverstock A, Finlay F. Specialist registrars' emotional responses to a patient's death. *Arch Dis Child* 2006; 91: 774–76.
16. Rose SC, Bisson J, Churchill R, Wessely S. Psychological debriefing for preventing post traumatic stress disorder (PTSD) (Review). *Cochrane Database of Systematic Reviews* 2002; 2: CD000560.

The author's e-mail address is: y.michele.wang@gmail.com.