For Our Patients, for Ourselves: The Value of Personal Reflection in Oncology

Lidia Schapira, MD, Jane Lowe Meisel, MD, and Ranjana Srivastava, FRACP, OAM

OVERVIEW

Caring for patients with cancer is a great privilege as well as an emotionally and intellectually challenging task. Stress and burnout are prevalent among oncology clinicians, with serious repercussions for the care of patients. Professional societies must provide guidance for trainees and practicing physicians to mitigate the negative consequences of stress on their personal lives and medical practice. Reflection, reading, and writing about personal experiences provide outlets for fortifying personal reserves and promoting resilience to allow us to recognize the joy and meaning of our work and to forge connections with our peers. Herein, we present some of our own reflections on how and why one might take time to write, and about the power of the written word in oncology and medicine.

In the field of oncology, we are all connected by our desire to improve the lives of patients afflicted with cancer. However, whether one is primarily clinical or spends most of his or her time conducting research, the work can be inspiring and humbling, while proving tremendously difficult. In a professional landscape that values clinical and research productivity by numbers of patients seen and manuscripts published, reflection can serve to provide perspective and maintain some balance in our personal and professional lives.

I attended a progressive junior high school, governed by the philosophy that 12- and 13-year-olds are often so focused on their emotional lives that this reality needed to be incorporated into the curriculum rather than ignored. Therefore, in class, we were assigned to write about our personal experiences. Delving into our emotions in our writing and then sharing our pieces with the class allowed us not only to understand the power of the written word and to aspire to harness it but also to connect with one another at a time that can be inherently insecure and lonely.

Oncologists are very different from seventh graders, but the process of putting our experiences into words and sharing them with others is, in many ways, even more important. This process can help us make sense of difficult conversations with patients, the impact of our work on our home lives, or challenges encountered in the laboratory. In a recent survey conducted by ASCO evaluating burnout and career satisfaction, almost 45% of the nearly 1,500 oncologists surveyed were burned out on the emotional exhaustion and/or depersonalization domain of the Maslach Burnout Inventory. More hours spent on patient care were positively correlated with the risk for burnout, a concerning finding given the projected shortage of oncologists over the coming years and the need for many of us to start seeing higher volumes of patients.

Burnout happens not just because we are too busy but also because many of us do not have a way to process, either by ourselves or with our colleagues, the gravity of our experiences and what they mean to us. Consider this: many of us, as our stacks of medical journals arrive in the mail, turn first to the New England Journal of Medicine's "Perspective" section, JAMA's "A Piece of My Mind," or the Journal of Clinical Oncology's "Art of Oncology" (AOO). We devour these pieces, hungry for stories and looking for connections. It was through this lens that our session on the use of narrative in oncology was conceptualized.

We believe that reading and writing about our experiences may allow us to achieve greater self-awareness and more of a sense of community among colleagues and, through this, allow us to be better at what we do and to derive greater enjoyment from it. What follows here is a personal account of the journey of one inspiring and prolific oncologist-writer, Dr. Ranjana Srivastava (Part I), and a piece on the power of stories from Dr. Lidia Schapira, the current editor of AOO (Part II). Our hope is that these reflections will inspire our readers to think more deeply about the power of narrative in our field and the different ways they might use it to further their own personal goals.
PART I: THE WRITER’S JOURNEY

It was nearing the 10th anniversary of the loss of my twin pregnancy when I felt an urge to write about it. I can’t say that I had been dwelling substantially on the loss or that the 10th year felt any more significant than, say, the 1-year or the 5-year mark. If truth be told, life had been very good to me after that tragedy, with the healthy arrival of three children, a fulfilling profession, and much more. The valuable perspective gained from a career as an oncologist meant that my grief wasn’t as paralyzing as I had feared. But clearly, as the anniversary approached, the event must have been somewhere in my subconscious because I felt the need to expunge it.

That column ended up becoming one of the world’s most widely read and shared columns in the Guardian that year. What touched me most was the tenderness and humanity of exchanges the column elicited in what truly felt like a global village. Complete strangers sent me their wishes and forwarded the essay to others going through the same experience. Voltaire was right: writing is the painting of the voice.

I am a medical oncologist and writer. I have written books and essays, and for the past few years, I have been a regular columnist on medicine and society for the Guardian, which was founded in 1821 as the Manchester Guardian and now has a global reach. I am also an essayist for the New England Journal of Medicine. In this personal reflection, I will track my own journey while answering some of the commonly asked questions of why, what, and when to write.

Why Write?

This is the easiest one. As oncologists, we are witness to life’s deepest and most intimate moments. These moments move, inspire, frighten, teach, and challenge us. Who do we tell about the pregnant mother with advanced breast cancer or the successful businessman with metastatic melanoma who goes from diagnosis to death in 4 weeks? Who will share our heartache at looking after a grandfather whose greatest lament is not that he is dying but that his children can’t find the time to visit? Who will admire with the same intensity the patient whose face glows with dignity and courage even as cancer invades her skin? Our patients stir a range of emotions with us, not all of which we necessarily feel like speaking aloud. We fear that our family and friends may not understand us or that they may find our stories gloomy or upsetting. But we know that acknowledging our raw emotions, our learnings and feelings, is critical if we are to be better doctors. Human beings find meaning through stories, we connect through stories—and our stories demand to be written, though not everything we write needs to be published.

I started writing when I was 11, but it is only in the past decade that I have started publishing widely. Most of what I write is for private consumption, catharsis, and making sense of the world. My writing centers me; knowing this means that if the market for my writing were to fall away, I’d still gain personal satisfaction from the habit.

What to Write

The history of medicine is replete with fine writers, and it’s really no wonder when you think of the fertile grounds for writing that being a doctor provides. We just have to turn up to work to stumble upon stories. The lives of our patients and our own lives intertwine to provide us with rich experiences and powerful learnings, and as long as we tune into human stories, there will never be a shortage of ideas.

However, one thing that concerns doctor-writers is the matter of consent. Is it ethical to write about our patients, who trust us with their secrets? Should one always seek consent when writing? What happens if we unintentionally end up offending a patient, or for that matter a colleague, through our writing? The impetus, and the temptation, to be published can exert such a pull that it’s easy to cross the line between telling a story and breaching patient confidentiality.

Something every modern writer must be aware of nowadays is that writing has an unprecedented digital footprint. Once you hit send, you can’t control the ways your work is read, interpreted, and used. It is also always and readily available, even if you’d like it to go away. This is something I have become increasingly aware of in writing for high-profile platforms such as the Guardian and the New England Journal of Medicine. Editorial assistance is important, but it’s just that, assistance; as the author, one must own and defend one’s writing.

It is impractical and unnecessary to always get consent to write. Furthermore, I think that the very act of seeking consent changes the nature of writing—it’s difficult to render a totally honest interpretation of an event and write without fear or favor. At the same time, no doctor wants to hurt a patient or jeopardize a valuable and therapeutic relationship. Because I write almost exclusively about patients, here are some rules of thumb I follow.

I ask myself why it’s important to write about what happened. Is there a meaningful and universal message to share? Could what I write inform, educate, or empower someone? Or is it because I am annoyed and need to vent? I work mostly in a highly socioeconomically disadvantaged community with a high proportion of non-English-speaking
refugees and asylum seekers. It’s safe to say that the vast majority of my patients would never come across my writing, but I always ask myself how they would feel if they were to stumble upon it. Would they be hurt, or would they feel heard? Would they feel exploited or understood? Would they say I had misrepresented them, or would they consider me their advocate?

There are things I never write about without prior consent. These have included attending the funeral of a patient I was fond of, acknowledging a gift from a dying patient, reporting an intimate but unique consultation, and encounters for which it would be immediately obvious to a reader that the story was about him or her or a loved one. No one has ever withheld consent when I have explained the reason for my writing; patients and their relatives are very generous and thoughtful in offering their experiences as teaching moments. Across many years of writing, I have attracted the ire of only one patient, who believed that I had been loose with the facts of her case. She chastised me for abusing my position and refused to accept my apology. In fact, her story was an all too common one, but in telling it, I had obviously skirted unacceptably close to her personal experience. This was one of the lowest points of my writing career, as I felt guilty about causing a dying patient distress and sad that I had not had an opportunity to make amends. But her rebuke has stayed with me and made me more cautious and more considerate.

Ultimately, writing about medicine relies on personal integrity and having a moral compass that detects right from wrong before an editor or one’s audience has the opportunity to do it. It means thinking deeply about one’s intent, endeavoring to set aside personal bias, and then having the courage of one’s conviction.

Finally, this is a one-line mental checklist I tick each time I write: “Will I be able to hold my head high in clinical tomorrow if I publish this?”

When to Write

“How do you find the time?” I once asked a famous writer. “And what do you do about writer’s block?”

“Nonsense,” she said briskly. “When you show up to work, do you suffer from oncologist’s block? Writing is a job. It takes commitment.”

Several of my colleagues lament that they used to write well until careers in medicine put waste to their dreams of becoming authors. Now, between juggling patients, configuring career progression, and raising their families, they just don’t have the time to write.

A barrier I identified early on in my writing career is that the idea of having unlimited time, no distractions, a spotless desk, a cabin in the woods, or a house overlooking the ocean was never going to be my reality! With a busy clinical load and young children, there was never a good time to write. I spent the day doing my regular job, and by nighttime, I was too exhausted to write.

But I never gave up writing a journal, filling it with mostly mundane observations and reflections, not realizing that the mere habit of writing was important. I stuck to nice pens and sought out beautiful leather-bound journals to enhance the meditative quality of longhand writing.

But it didn’t feel like enough. Finally, the urge to write more and communicate with an audience became so great that I had to confront the reality: I could either write amid the chaos of work and home or not write at all. So, slowly, I trained myself to write among the chatter of children, keeping an eye on the trampoline and another on the screen. I became adept at stealing moments to write: between school pickups and sports drop-offs, while waiting in the car for swim school to finish, or perched on the edge of a bath. I learned to write a few lines if a patient unexpectedly canceled or if a meeting was delayed. I also learned to write in my head when I went jogging. Going for a run in the early morning before the hustle and bustle of the day begins is a fine way of sifting through my thoughts. Now, with a deadline every fortnight, I must and can write almost anywhere.

I have no set time to write, but I do know that when an encounter lingers in my mind, it’s a signal to write. I turn the encounter in my mind, let myself feel uncomfortable or challenged or gratified, until gradually the essence of the experience becomes clearer and I am ready to write. Then, the words seem to tumble out. The hardest part of writing is getting started. Now, I worry less about perfection and more about getting the words down on paper. It’s much easier to edit than get started.

I have had to make some compromises. I love the slowness of writing by hand, which allows you to turn your thoughts in your mind, but I can write like this only in my journal now. The rest of my work is done on a laptop, but because I don’t like carrying it everywhere, I save my work in the cloud so I can access it from anywhere in the world. In the same way as many people work on talks and presentations in the airport lounge or on a flight, I write wherever I can.

But perhaps the most deliberate, and the hardest, decision I have had to make is to not undertake full-time clinical work to make some room for writing and its necessary companion, reflection. This has inevitably meant somewhat restricted career opportunities, with academic and financial ramifications, but for me it seems like a fair price to pay for the tremendous job satisfaction of being a doctor and a writer, able to serve not only my patients but a world of people. To have a few hours in the week to read widely, experiment with different forms of writing, and reflect upon the meaning of being a doctor seems like a luxury that many of our time-starved, emotionally fatigued colleagues are eager to embrace. They need to know that if good medicine is about advocacy, we can serve society through various means. Research and clinical work are two time-honored means. But writing and public speaking are legitimate means of democratizing medicine.

The celebrated physician and writer Anton Chekov observed, “Medicine is my lawfully wedded wife and writing my mistress. When I tire of one, I spend the night with the other. Though it’s disorderly, it’s not so dull, and besides neither of them loses anything from my infidelity.”

ascmo.org/edbook | 2017 ASCO EDUCATIONAL BOOK 767
Nurturing the art of medicine through reflection and writing is important. It allows the development of a therapeutic, creative, and educational outlet. We must not consider it an unaffordable luxury but an essential tool for improving our own lives and those of our patients.

**PART II: THE POWER OF STORIES**

**A Case for Reading**

Reading essays published in medical journals gives us the opportunity to reflect, alone and collectively, on important aspects of practice that are essential but often overlooked. Ethical dilemmas come into sharper focus, and the emotional toll of practice is assuaged by feeling connected to peers or to the writer. Even if we read when we are alone, the act of reading establishes a virtual connection to the writer, editor, and fellow readers. It provides a form of social support that is so often lacking in the workplace and offers validation of the experiential and intellectual aspects of our complex professional lives. Doctors have traditionally kept their worries to themselves and paid a price for their stoicism and emotional isolation. By stimulating reflection and conversation, reading can foster self-awareness and self-expression. Furthermore, reflecting on one’s reaction to text nurtures our sense of purpose and vocation, helping us maintain perspective and balance in our lives. Reading a story or personal reflection forces us to slow down and inspires us to daydream. In those moments when time seems suspended, we allow our minds to roam, occasionally stumbling or straying, always searching for what is normally tucked behind conscious thoughts and hardly ever allowed to surface. We connect with our sense of vocation, with ideas we once cherished and then discarded or forgot, and with desires we may not have known existed. In the act of reading, we are lifted and transported by the creativity of our peers, whose artistry gives us new insights into old problems and language to describe what seemed beyond the reach of words. Stories, poems, photo essays, and commentaries provide a platform for reflection that allow us to explore other perspectives and other ways of being in the world. In other words, reading stimulates our empathic abilities, bringing ideas and dreams into sharper focus.

Stories and opinion pieces serve another useful professional function, in that they shape our professional discourse. I can easily quote essays that shaped my views on important topics; their messages remain fresh and powerful years after publication. We also learn, from our colleagues’ experience, how to frame and discuss challenging topics so that our communication is clear and supportive. Stories and reflections expand our vocabulary and our mind-set, at times providing guidance and focus that can improve our clinical performance. Reading can, by all of these mechanisms, help reduce perceived levels of work-related stress and even contribute to our well-being. Perhaps reading even helps reduce the risk of professional burnout, although this is impossible to prove. What is clear, however, is that the ability to remain curious and to imagine something that does not yet exist is indispensable for success in research and innovation.

Composing a persuasive and coherent narrative is also essential for achieving one’s goals on personal and professional fronts and may contribute to professional satisfaction. Successful grant writers persuade readers to invest in their dreams. Trusted mentors help junior colleagues bring their ambitions and projects into focus. Clinicians function as coditors for their patients’ narratives through attentive listening and deliberate communication. Thus reading serves to prepare us for the work of empathic listening.

Reading also brings us into contact with talented storytellers. Listening to stories provides another powerful venue for enjoyment and has become easily accessible in the era of podcasts and audio books. Stories can keep us company on our commute to work or while sitting in the car waiting for a child to finish practice or during workouts. We can read privately, quietly or out loud, and reread at our own pace. Stories are extraordinary tools for teaching ethics and interpersonal and relational skills. They give us access to complex emotions and deepen our appreciation for another’s suffering or heroism. Stories surprise and entertain us, expand our intellectual reach, and challenge our creativity. Persuasive commentaries can influence opinion and have a transformative effect on education and practice. Because we inevitably spend so much of our time reading medical notes, scientific papers, and manuscripts, reading stories provides a welcome escape into a world of colorful characters, poignant storylines, and insightful messages.

Essays published in medical journals are often personal narratives written by one individual, although increasingly these narratives have multiple authors, suggesting a collaboration and a team effort. They are selected for publication on the basis of their messages, originality, and artistry, as well as their perceived relevance for the community of readers, and this varies depending on the orientation of the journal. Editors envision that readers turn to text as a springboard for reflection and that they appreciate writers’ willingness to share personal doubts, to expose their vulnerabilities, and to let us peek at their inner landscapes.

**"Art of Oncology" in the *Journal of Clinical Oncology*: The Stories We Tell**

The *Journal of Clinical Oncology* has invited the submission of personal essays, poems, and art forms for publication within the "Art of Oncology" section since 2000. Since its inception, AOO has published essays on a broad range of topics that represent the human side of cancer from the perspectives of patients, advocates, and clinicians. Under the skillful leadership of Charles Loprinzi and then David Steensma, AOO struck a chord with the global readership of the journal. I had the privilege of succeeding Dr. Steensma as consultant editor at the end of 2014, and I enjoy working with a brilliant and wise editorial board to select submissions we feel contribute to shaping our professional culture. We look for essays that have timely and relevant messages, written with humility and candor.
Great essays capture our attention from the start. Some are funny or whimsical, others sorrowful or nostalgic. Through an assortment of storylines and scenarios, we travel imaginary roads and grapple with common dilemmas. Essays help us witness others’ suffering and celebrate their heroism and provide a safe release for the emotional toll of working in oncology. Despite enormous scientific progress, those of us involved in the care of patients know the grief and sorrow that accompany a career in oncology. Reading can help us get through a tough day.

Writers write about what they know. Doctors and nurses spend a lot of time listening to stories and are familiar with plot, protagonist, setting, dialogue, and theme. Oncologists struggle to find meaning in tragedy and humor in daily minutaie and to maintain a healthy balance between their work and home lives. Several essays addressed these issues in the past year. In “What Mommy Does,” Melissa Mark describes her struggle to shield her young daughter from learning that her mother’s work involves the care of children who are dying and how this changed after the child overheard a telephone conversation with a hospice nurse while taking her evening bath at home. Megan Caram coins a new term, “oncologist’s guilt,” to describe the conflicting emotions she experienced during her 3-month maternity leave. She describes feeling as if she were “abandoning” patients and contrasts the healthy period of attachment between a newborn and his mother with the feelings of dependence that are inherent to close therapeutic relationships.

William Meyer shares his heartbreak over the death of his own grandchild from cancer. His inner pain is almost palpable as he writes about feeling a sense of “abject failure to help the ones most dear [to you] despite years of training and supposed ‘expertise.’” He concludes the essay on an unsettled note: “these are not easy feelings to come to grips with, and perhaps the sharing of further insight on these experiences will require the passage of time.” Indeed, with time we can find meaning and integrate painful experiences into the larger tapestry of our lives, as told by Jonathan Finlay in “A Ruby Anniversary.” On the 40th anniversary of his last “encounter with seminoma,” he embraces his fortune and believes he is a better physician because of his own experience as a patient with cancer.

Coming to terms with grief and loss is a recurrent theme for AOO. In her remarkable essay “Pieces of Grief,” Erica Kaye describes the visceral reaction she experienced after the death of a patient in the intensive care unit, a death that forced her to face her emotional exhaustion. Katherine Reeder-Hayes describes being overcome by emotion and crying, as she is standing alone in her new, empty home at midnight, listening to bluegrass playing on the radio, a paintbrush in her hand. Reeder-Hayes writes about beloved patients, whose passing affects us very deeply. Daniel Rayson explores both sides of the clinical relationship in his wonderful essay “White Knuckling.” He delves into the lived experience of a young, dedicated oncology nurse who is experiencing symptoms of burnout and trying her best to encourage and comfort her patient, a tough, retired natal intensive care unit nurse who voices her ambivalence about continuing to fight her metastatic cancer, fully aware that she will die of this disease. Rayson captures the imaginary dialogue that occurs in the infusion unit, while the patient receives her infusion of bisphosphonate, giving voice to the trauma experienced by oncology nurses who are on the front lines of cancer teams, delivering solace and cheer together with powerful anticancer therapies.

Authors write to share their stories and to give advice. Laura Melton draws a parallel between a patient who successfully compartmentalized his illness until the very end and clinicians who cope with loss by compartmentalizing their feelings. She acknowledges that this emotional distancing provides a buffer that allows “us to be fully present without feeling overwhelmed” and also warns us that artificial boundaries are porous and may crumble during transitions between work and home life. David Korones writes about caring for an adolescent with a pontine glioma who insisted that she did not want to know her prognosis, describing the tension he experienced in trying to reconcile his patient’s request not to know with the evidence supporting full disclosure of prognostic information.

Reading through these essays, we find common ground with colleagues we have never met. Essays also serve to express regret and remorse, as in Nikhil Barot’s tale of a patient who died of complications of an unwanted diagnostic bronchoscopy. The author wishes he had listened more carefully when she refused the procedure and asked to be allowed to go home to die, ending his story with a very simple and effective “and you sit and think and think.” Reena George expresses remorse at having judged and dismissed the unreasonable requests from the daughter of a patient with advanced cancer, until she understood that they stemmed from a desperate and loving desire to help her dying mother. These sincere reflections can be therapeutic for both writer and reader.

CONCLUSION
Cancer clinicians need stories to recalibrate their emotional lives, to make sense of their experiences, and to learn from one another. Writing can serve as an outlet for self-expression or a mechanism for making sense of complex experiences. Writers write for fun, for therapy, to share stories and opinions, to honor a patient or colleague, for atonement, and sometimes for the glory of being published. Essays bring joy and insight to readers, allowing them to slow down and reflect and to refuel their emotional reservoirs.

It is our hope that reading also stimulates dialogue and helps foster a culture of collegiality among oncologists. Talking about our reactions to the written word can help us get to know one another and contribute to the professional development of junior colleagues and trainees. Reading, reflecting, and sharing stories serve an important role in the professional development of oncologists. Stories can guide us to find our own sources of inspiration and support and strengthen our therapeutic skills. In turn, this will affect the lives of patients and family caregivers struggling to cope with the unwanted burden of illness.
References


