Helping Patients Voice Their Goals of Care

BY MELISSA GORMAN, PA-C, MPAS

Working exclusively in inpatient medical oncology, I often care for people when they are quite sick, and at critical points of their illness. Because of the acuity of this setting, I frequently engage my patients and their loved ones in goals of care meetings to discuss their worries, hopes, and best- and worst-case scenarios, not only for their health care, but for their life.

Since starting my PA (physician assistant) career, I've had the opportunity to learn from my hospital's palliative care team and have personally led and participated in many goals of care conversations. Something I did not anticipate was the impact of patients expressing things like, "I wish I would have known to think about 'X' sooner," or "I wish I would've done 'X' differently, but now it's too late." It's heartbreaking to hear patients voice sentiments like these, especially if there *was* an opportunity to fulfill what they'd hoped for. In the moments when patients voiced something like this, I found myself thinking about how things might be done differently, or sooner. Particularly, how to help patients better identify and articulate what is most important to them, so their team can better discuss next steps and how they may or may not impact that patient's goals.

How might we as providers better help patients, caregivers, and families weigh factors they may not know to consider? How do we get information to them sooner within the care continuum? Are the resources available, but patients are overwhelmed and finding it difficult to identify how they feel? How can we equip patients to have more engaged conversations with their care team? I hoped that doing so would lead to even better patient outcomes, interactions, and satisfaction—but most importantly that these touchpoints would give patients back a sense of self, empowerment, and support that can easily falter in the midst of a life-altering diagnosis.

> Reflect on a time you felt truly loved and supported. Describe what that felt like and its impact on you. What does "quality of life" mean to you? What does good quality of life look like for you?
>
> — MELISSA GORMAN, FROM HER BOOK *CONTEMPLATING COURAGE: A REFLECTIVE JOURNALING COMPANION WHEN LIVING WITH CANCER*

Some people want to receive every treatment and test no matter how it will affect their quality of life, and that's their decision to make. Others do not, and we need to know that information, too. What's critical is knowing someone's true priorities before it's too late to honor them. Not everyone has access to high-quality palliative care programs, and even if they do, not everyone will take advantage of these services. Not everyone engages in deep, vulnerable discussions easily. Many people do not have access to professional psychological care, and if they do, many decline these services. It was this gap in care that I have witnessed so frequently that led me to create *Contemplating Courage: A Reflective Journaling Companion When Living with Cancer*.

Writing a book was something that I hoped to do maybe 10 or 15 years from now—later down the road when I have more experience and wisdom to share. But I did not anticipate the impact of hearing these "If only I'd thought about…" sentiments. While these words are not frequent, they are also not rare. I am fortunate to work in a health care system with incredible oncologists, cancer service lines, palliative care, psychologists, pharmacists, nurses, and care management teams with a multitude of resources, yet it felt like there were *still* a lot of people who needed more support, but in a different way. Inpatient, I am also caring for many people transferred for specialty care or procedures but who live and are treated within a more rural, resource-scarce system.

So, I pivoted. I decided that my long-term idea of a "Cancer 101" guidebook to provide some general direction for people living with cancer might not actually be that purposeful. Trying to empathize and relate to patients through statistics and stories of people I'd previously cared for felt invalidating and impersonal. While a book of research and experiences most definitely serves a purpose, I did not want to impose the feelings and experiences of others onto a patient whose most important story is their own. So instead, I aimed to create a book that would provide a space for people diagnosed with cancer to have an outlet. To just be them. To explore their feelings, thoughts, hopes, and fears on their own terms.

Striving for Care of the Whole Person

The journal itself is composed of just over 100 thought-provoking prompts, purposefully written to start from cancer diagnosis until end of life. This book also includes several prompts highlighting facets and moments in the life of the individual *separate* from their cancer, reflecting on moments and memories that define who they are as a person. Intentional word choice allows this book to support anyone living with a cancer diagnosis regardless of their age or gender, their type or stage of cancer, or how long it has been since their initial diagnosis.

There are a few pages in the journal that address misconceptions people may have about more difficult aspects of health, like hospice care and naming a code status. These are topics we often talk about with patients in the hospital, and I think engaging in these conversations is especially hard on patients who have not thought about these issues before being acutely ill. Further, it can be quite distressing for patients and their families to explore topics like hospice care or do-not-resuscitate forms when the patient is already tired and unwell in the hospital.

Once I had the idea to write a journal, the final piece came together quickly. Since I participate in a lot of goals of care conversations at work, I thought about the questions I ask my own patients and what they and their family members have cited as being particularly helpful. It started out as a passion project, so I did most of the formatting and design myself, then reached out to several publishing companies when I realized I *could* turn this idea into something real.

Fulfilling an Unmet Need

The purpose of this book is to provide a physical space for people living with a cancer diagnosis to reflect on all sorts of topics and issues: What's going well? What isn't? What do they worry about and what do they hope for? How might their team (family, friends, circles of support, and/or health care team) better support them? My hope was to allow people a space to just be themselves, without feeling a need to filter their feelings for their audience. To really think about what *they* want and need.

I often care for patients in the hospital who confess to adjusting their narrative to avoid burdening family or friends. For example, a patient shared that she now avoids telling her family and close friends when she is sad or struggling because, "It makes them sad, and sometimes they cry, and then I end up being the one comforting *them*." In these situations, patients say that they tend to "shut down" and "just act like things are okay," even if they do have things they want to talk about. I worry about the downstream impact if our patients do not have a space where they feel safe to transparently explore their feelings and process them.

A common fear and psychological challenge patients share is the unknown. I hope people find empowerment through the topics in this book. I have received feedback that patients using this journal felt a sense of "calm and relief" or "felt like [I] gained a piece of control and empowerment in [my] life" by writing things down.

I think it's imperative for people to first identify their own feelings, questions, and concerns before discussing them with others. This fosters deeper, more vulnerable, and transparent discussions with a patient's family, friends, and medical care team. Several prompts in this book are meant to uplift and bring up positive memories too. Ultimately, my hope is this book provides people with extra tools to feel supported, and helps individuals better communicate their wishes to those around them.

Designed for Reflection at Any Stage

Anyone can get something out of this book. Its prompts are purposefully written to apply to anyone living with a cancer diagnosis. Many prompts are about someone's cancer story: the ways cancer has impacted them, the ways it has not, and ways that may change over time. For someone facing a terminal cancer diagnosis, this book can help with legacy building, serving as a physical collection of handwritten notes and memories for family and friends to cherish after a loved one passes away. Many of the prompts are written to capture the pivotal aspects of someone's life: what they love and who they are, irrespective of their cancer.

I think this journal would prove most beneficial if introduced around the time someone first finds out they have cancer—primarily because I'm a strong advocate for providing access to and awareness of all available support resources when someone receives that diagnosis. But at the end of the day, I think anyone could benefit.

I put my heart into this book, drawing inspiration from memories of several patients and their loved ones whom I will never forget. In a perfect world, I think everyone should have a resource like this when they receive a cancer diagnosis. Not separate from traditional therapy or from their cancer care team, but as an additional layer of support. It has been so meaningful to hear that the journal is helping people, but in the same breath, it's something I wish no one would ever need to use. OI

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