

Finding Joy in Practice Cocreation in Palliative Care

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Four years ago, after nearly 20 years in practice, I walked out of the familiar world of infectious disease and into the world of palliative care. In the world I left, I cared for hundreds of patients, educated countless learners, led dozens of infection prevention efforts. But that world felt increasingly superficial, fragmented, isolated, a hard place to find joy and meaning in my work.

I discovered a different world in palliative care, a world that—I think I can say—embodies cocreation.^{1,2} Spend a day with me and see what you think.

The team is gathering, like it does every morning, at a large table in a windowless conference room: we are physicians, nurses, chaplain, social worker, healing arts therapist, fellow, residents, students. First we take a moment to center—some days we listen to a piece of music, or simply share a moment of silence. Today I read aloud “Promissory Note,” a poem by Galway Kinnell.³

Then we turn to bereavements, pausing for a few words about the two patients who have died since yesterday’s meeting. One of our senior clinicians smiles through tears as she describes “one of my three favorite patients of all time” and the final home visit she made just a day before her patient slipped into unresponsiveness. A fellow expresses his shock that a young man with sarcoma and what we thought was treatment-induced delirium died suddenly on the oncology unit overnight. “He didn’t see it coming,” he says. “Why didn’t I see it coming?” As we share details of these patients’ deaths, assessing the quality of the death, and the patients’ and their families’ readiness for it, we are assessing the effectiveness of our interventions and the risk of complicated bereavement for those left behind. We are also honoring the lives of people we cared for, and our work with them. We, too, grieve these losses.

Pulling up the outpatient schedule, we run through the list of names, some familiar and some not yet. The outpatient team hears about patients discharged yesterday, then hands off clinic patients newly admitted to the hospital, sharing information about pain management, family dynamics, prognostic awareness. “Hold this one closely,” we hear about one. “Wait to be called” is the recommendation on another.

Then we review the inpatients—seeking input from each other on active issues and challenges. Today our chaplain reflects on the spiritual suffering of a woman whose third cancer in a year has left her near death. The healing arts therapist tells of a massage session that eased intractable anxiety in a young man with cystic fibrosis. Back and forth we go, physician to chaplain to social worker to nurse. How might volunteers extend our reach here? Who can attend a family meeting at 2? How do I manage the feelings of sadness or helplessness this case engenders in me?

Each patient’s name is spoken; each person at the table has the chance to contribute.

As the meeting ends our first consult request comes in: “Widely metastatic cancer: clarify goals of care.” After reviewing the medical record, the clinical team heads to the wards. We check in with the patient’s nurse, then enter her room.

Early in the year, the attending physician leads the conversation while the fellow closely observes. Today our fellow leads and I become the active observer, ready to jump in if needed, but mostly there to pay close attention to his communication, using the clinical encounter as an opportunity to facilitate both learning and good care. From a chair close to her bedside, the fellow leans in. “What have you heard? What are you expecting next?” he says. From behind horn-rimmed glasses, her eyes lock on his. “It’s overwhelming,” she says and sinks back into her pillow. Asking open-ended questions, the fellow explores this woman’s experience of newly diagnosed lung cancer, gently probing her understanding of the prognosis, hearing her worries about what will happen to her beloved Labrador retriever if she can’t return home. In a steady voice he poses questions for her to consider: “What if time is shorter than we are hoping for? Would you do anything differently?” Gradually he helps her construct a narrative that incorporates goals that are achievable, helping to restore her agency in the face of an unwanted diagnosis. After the encounter, we find a quiet place and debrief the visit, reflecting together on what we each noticed, what it meant, and how we will build on it as we help her navigate her remaining weeks.

Then it’s on to the intensive care unit for a family meeting: an 80-year-old man is not waking up after severe head trauma, and his family is uncertain about what to do. We spend time with the man’s wife and son first, learning what things are most important to this man: his fly fishing, cutting and splitting the wood each fall, reading the *Wall Street Journal* every morning as he eats his oatmeal. “He’s been a good provider,” his son said. “He has taken care of us.” Then we join the family in a meeting with the neurosurgeon and the intensivist. We learn that the bleeding in his brain is extensive, that the chance of his waking up at all is slim, the likelihood of walking, feeding himself, living outside a facility even slimmer. We share with the team what we have learned about this man and what is important to him. The neurosurgeon pauses, looks at the man’s wife, then his son. “He will not fish or read the paper again. Without the ventilator, he would have died already. Our machines are keeping him alive.” His wife puts her head in her hands, her shoulders shaking. Her son reaches an arm around her, and,

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in a voice that grows stronger as he speaks, says, "He would not want this." His mother nods, her voice almost imperceptible. "I know," she says. "This is hard," I say, reaching out to touch her hand. A few moments pass and then they ask, "So what do we do now?" We outline the process of withdrawing life-sustaining treatments, to allow this man a natural death while we treat any discomfort or distress to ensure that his dying is peaceful. We encourage the family to spend time with him, saying their good-byes, offering to visit again later in the afternoon. The wife wipes her tears, and smiles. "Thank goodness he finished stacking the wood last weekend," she says, and we all laugh. As we leave the room, she takes my hand in hers. "Thank you," she says. "It feels good that you know who he is."

It's funny how the world of palliative care, which each day brings us face-to-face with illness, with mortality, with heartbreak, is not a place of overwhelming sadness. Each day, instead, we find (or perhaps we cocreate) meaning, and even joy in our work.⁴ What core elements of our practice allow this to happen? Three strike me as important—you may hear others.

First, while our work elicits and honors patients' preferences,⁵ it is really about closing gaps between their hopes and outcomes that are medically achievable. This bridging work facilitates the cocreation of shared goals and realistic, actionable plans that get patients closest to desired outcomes while protecting them from in-

terventions that will not help. For teams, working toward shared goals promotes a sense of meaning and even of pride, which is elusive when goals are misaligned.

Second, our work is grounded in narrative practice.⁶ We have the privilege of exploring the unique stories of others and of helping to coauthor the next chapters. Regular reflection on our responses to these narratives—and to our own—often using the lenses of literature, art, music, and spirituality, deepens our self-awareness and empathy and is fundamental to our professional formation.

Finally, our work is deeply collaborative. We function from morning to night as an interprofessional team engaging across a range of settings. Learners are fully integrated and not left to "learn by doing." No one works in isolation. Instead, our interdisciplinary community of practice is a sustaining resource as we witness suffering and work together to ease it.

Back in the team room, another day is winding down. Coat zipped, backpack shouldered, the intern who is rotating with our team pauses at the door as he prepares to head home. "My wife asked me last night what rotation I am doing. She said I seemed ... happy." Those of us still sitting around the table typing the day's notes smile. He does too. "See you tomorrow," he says and the door swings shut behind him.

Meeting Presentation: A shorter version of this piece was presented at the ABIM Foundation Forum, July 2016, Stevenson, Washington.

Conflict of Interest Disclosures: The author has completed and submitted the ICMJE Form for the Disclosure of Potential Conflicts of Interest and none were reported.

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