Caring for one of our own

When you're caring for a patient and friend, who was recently your colleague, working out boundaries and negotiating the particular privileges and pressures of caring for them can be hard. The problem was explored in a Schwartz Center Round* at the Massachusetts General Hospital.

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The patient is a 52-year-old male nurse who presented with metastatic pancreatic cancer. Prior to his illness, he was in great physical shape. He had worked in the inpatient cancer unit of Massachusetts General Hospital (MGH) for almost 30 years. He developed hip pain and was ultimately found to have lytic bone lesions. Computed-tomography scans showed a mass in the pancreas with liver metastases and extensive bony involvement. A biopsy confirmed a diagnosis of pancreatic cancer.

Schwartz Center Round

Nurse Director

"After the patient became ill, he was admitted to our unit twice, each time for several weeks. The challenges in his care arose precisely because he was one of our own. We wanted to do the best for him because he was a nurse – and one of our nurses. There were privacy issues related to the delicate balance of independence and involvement. The staff on the unit did a fabulous job figuring out how to set boundaries while providing the best possible care."

The Oncologist®

This article was first published in ***The Oncologist*** vol. 19, no. 5, and is republished with permission. doi:10.1634/theoncologist.2014-0079

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Primary Oncologist

"Both the patient and his family made it very clear that he wanted a very aggressive approach. He had a difficult time moving because he was in such pain; his performance status was 3 and he was not a good candidate for aggressive chemotherapy. But here was a man only in his mid-50s, and we knew he was in pain because of the cancer and it was the pain that prevented him from being physically active and more mobile. So we decided to give him our most aggressive chemotherapy (5-fluorouracil, oxaliplatin, irinotecan, and leucovorin [FOLFIRINOX]) and palliated his hip pain with radiation, intravenous analgesia, and a bisphosphonate. Even with maximal analgesia, he still had a tough time walking. We were clear and honest with him about his dire prognosis, but he wanted to continue receiving treatment as long as he could tolerate it. Interestingly, the tumour markers plummeted, suggesting response to treatment, but his pain did not get better. We continued chemotherapy in the face of these contradictory findings until it became very clear that treatment was futile and we needed to change the goals of care."

*Schwartz Center Rounds are monthly multidisciplinary meetings where caregivers reflect on important psychosocial issues that they, along with patients and their families, face and gain insight and support from fellow staff members, with the goal of advancing compassionate health care, supporting caregivers, and fostering the connection between a clinician and his or her patients.

Embracing one of our own

Primary Oncology Nurse

"I did not know this man before he was a patient. In order to meet him, I had to squeeze through a crowd of people in scrubs at the door of his hospital room. For me as well as for the nursing staff, the number-one issue was dealing with so many visitors. Everybody had a special reason: "He'll want to see me …" We discussed it with the clinical nurse specialist because it was disrupting the atmosphere of the entire unit. The patient wanted to do everything with everybody, and there were plenty of people willing to join him. This exhausted him and he found some of the visits draining, but he had a tough time saying no. Many times he was on the computer in the room looking up his own laboratories or I'd find him adjusting his intravenous pumps, and I had to talk to him about just being a patient."

Palliative Care Nurse Practitioner

"My sense from this patient is that he felt comfortable being at MGH because this was home for him. He'd been an employee here for decades and did feel well cared for. But I think that just as we struggled to find a balance between professional and patient boundaries, he too struggled with it and how it affected his identity. 'Am I a patient? Am I a nurse?' We asked ourselves if we would want to be hospitalised and cared for in the same hospital where we work. He trusted his caregivers, and as his disease progressed, he started to relinquish the role of nurse."

Nurse Director

"Some nurses elected not to care for him because they felt that they were too close to him personally to care for him in a professional role. There was a sense shared by the staff of wanting to grant him his wishes because the situation was so terrible. A group pulled together and invited a football player from the New England Patriots to visit him. Others made big posters for him and brought in pictures. People really cared about him.

"He worried about his family, especially his 90-year-old mother. He had 10 siblings, all with different opinions. He would often take a passive role in their presence and did not show them that he was aware of how sick he was. Or if he did, they had difficulty hearing it."

Vulnerability

Primary Oncologist

"Caring for this patient was a real challenge. Most of his cancer care occurred in the hospital. I had seen him a few times in the office; he was always accompanied by several people, usually his sister, who is very vocal and assertive. When I visited him in the hospital, he was typically receiving pain medications, and I often wondered if he really understood what was going on. He'd ask me simple questions such as, 'Am I going to make the cancer go away?' I really wasn't sure that he could deal with reality. It was hard to say, 'You are going to die from this cancer' because there were family members on the edges of their seats asking me, 'What are we going to do next?' There was no indication that they ever wanted to stop his treatment. Every once in a while, the patient would say something to the effect of 'Oh, so in a couple of years from now, can I go back to work?' He never asked 'When will I no longer be able to function?' That topic never came up. He always thought he was going to get better."

Audience Comment

"I have a comment about the blurring of boundaries and vulnerability. What strikes me in listening to this is the parallel between what people are saying about the experience of the patient – that he had to allow himself to be truly vulnerable to be a patient at MGH, giving up the autonomy that people hang onto in other settings – and that the professionals who took care of him describe that same vulnerability, and that we feel it now, hearing his story. It's about people having to acknowledge vulnerability; it makes us understand where the source of our compassion originates."

Nurse

"One of the things I found interesting was that the family appeared to think that our Cancer Center owed this patient something. They expected a lot from us. We got a lot of push back from the case managers who

would say, 'This patient is not meeting level of care and should be at a rehabilitation facility or at home.' Typically, the family's response was, 'He worked here for 30 years and now you're pushing him out the door?'"

Primary Oncologist

"I think everybody should be treated with the same respect. The team became very creative in finding ways of meeting the family's requests."

Inpatient Oncology Unit Nurse Director

"The patient had moved in. From the beginning, we received him with the message that we would care for him and set his expectations accordingly. As time went on and we tried to discharge him, he was reluctant to go. He didn't want to go to rehab. He would say, 'What are you talking about? I'm going to stay here.' We felt guilty and conflicted."

Transition

Inpatient Oncology Nurse Practitioner

"During his last hospitalisation, he came to the point of needing to choose suffering through the pain or taking enough medication to make him sedated. And so one Saturday morning, I walked in and talked to him. He said to me he was 'ready' and did not want to be in pain anymore. And, somehow we got to talking about his family members and his discomfort with expressing this wish directly to them. I offered to do this for him. He said, 'I just don't have a backbone with them.'

"I called his family that Saturday. It was a beautiful day and they were sailing on the Charles River. I talked to his mom, who had put me on speakerphone. I told them we were going to focus on comfort and this meant pain medicines only, without any further blood transfusions or other interventions. His mother's response was to ask if we could put off the decision for another day. I responded that our patient had already made his decision and we need to respect that choice. I think he had a really hard time letting go. He remained on our floor but was transferred to Hospice."

Time pressures

Primary Oncologist

"I felt torn and unable to be physically present at the bedside as much as I had hoped. Our schedules revolve around outpatient clinics except for the weeks during which we are the designated Oncology Rounder. I couldn't come up there every day. My colleagues certainly had the expertise to make medical decisions, but I was still paged to attend family meetings. I would attend at least once or twice a week to have discussions."

Physician Moderator

"Did you feel somehow that you were not giving the patient the kind of treatment or care that he requested or that you would like to deliver to your patients?"

Primary Oncologist

"Absolutely. There are days when I look at my job as triaging in a MASH unit [army field hospital]. I look at my list of patients for the day and I say, 'What do I have to get done?' The phone calls that come in, the 200 emails a day I get. During some of this patient's hospitalisations, I had six or seven inpatients in different units. So how do I give enough attention to all of these matters without putting a couch in my office and just forgetting about going home?

"If I know something serious is happening to one of my patients, then I have to find a way to make it there that day, even if it is 9.00 p.m. That may mean I don't see another patient that day, but not because I don't care about that individual.

"I can only imagine how I would feel if I were the patient and I wonder how I would react, because I wouldn't be happy if my doctor wasn't there. My patients are so gracious and they seem to understand it. I don't know how understanding I would be if I were the patient."

Saying good-bye

Palliative Care Nurse Practitioner

"This patient had a really large and very caring family. They had great intentions. They all had very strong opinions and all wanted the best for their sibling. My sense was that, in some ways, the patient had difficulty communicating his prognostic awareness

to his family because of his own anxiety around it. I think he was protecting his family. He knew his family needed to feel that it was advocating for him, and that it had done everything possible. Once the family members were able to acknowledge and recognise his wish, they did not find it difficult to change course."

"I'll never forget the day he died. His family was standing by his side. The nursing staff was trying to keep the room very quiet, but the family spoke very loudly to him, 'We love you. Don't be afraid. We're going to be okay.' And it was a very tender moment. I think it reflected just how much, and how quickly, they were able to come to terms with the fact that he was at peace. So there was this very quick, very rapid transition. After he passed, Father George, the Catholic priest, came and led a beautiful prayer with the family."

Discussion

Caring for a colleague requires thoughtful evaluation of the usual and unique boundaries in optimal care. Caring for a staff member – "one of our own" – intensifies what is at stake and adds a level of complexity. Taking time to reflect and examine the issues, either from principles or particulars, provides an opportunity for informed and compassionate clinical practice.

Cultural changes in medicine

William Osler, deemed by many to be the father of modern medicine, is credited with formalising the detached air cultivated by many physicians in earlier generations[1]. The equanimity that he displayed has frequently been misinterpreted as aloof distance. In recent decades, the image of the master physician has evolved into one of a humane clinician with strong interpersonal skills who practices evidence-based medicine and is engaged in lifelong learning.

In order for young physicians to graduate from their medical training, licensing boards now demand that they demonstrate the following: compassion, integrity, and respect for others; responsiveness to patient needs that supersedes self-interest; respect for patient privacy and autonomy; composure during stressful situations; accountability to patients and society; and sensitivity and responsiveness to a diverse patient population.

Boundaries

Social and professional boundaries exist to help us best serve the patient and to protect our personal integrity by establishing a professional code of behaviour[2]. It is widely accepted that doctors should not care for their own family members because they will not be able to maintain the necessary objectivity and detachment in critical or stressful situations. Decisions may be made for the patient, rather than with the patient. Crossing the boundary into friendship with a patient can create a shift in the power structure that parallels the familiarity of caring for one's own family member. Getting too close can make it more difficult to confront this patient on noncompliance issues or to impart bad news[3]. It is understandable, especially under conditions of time constraints and organisational pressures, that it would be easier to fall into a casual conversation with a 'friend' than to deliver a methodical and comprehensive recommendation.

Sometimes it is hard to know exactly where to draw such boundaries. After all, we celebrate the healing connections between patients and their professional caregivers and promote personal engagement and compassion. 'Getting on the same wavelength' with a patient can be achieved in many different ways: personal disclosure, exploring common ground and shared interests, and sharing empathic responses and rapport-building or humorous exchanges, to name a few. Personal disclosure is a powerful communication tool, when used deliberately and with therapeutic intent. It can also prove risky and lead the patient to imagine the physician is sharing personal information for his or her own benefit or amusement or hinting at a personal and closer relationship when often none is intended.

A study of 1265 patient interviews found that patient satisfaction was affected differently by self-disclosure depending on whether the doctor was a surgeon or a primary care physician

(PCP)[4]. PCP visits including self-disclosure were rated as being significantly less reassuring than those without (42% compared with 55%, respectively; P=0.027), whereas for surgeons, it had the opposite effect (59% vs 47%; P=0.044). Perhaps patients value manifestations of humanity in stressful situations, especially when meeting experts known for their technical skills, but look for signs of competence in those in whom they trust for longitudinal care.

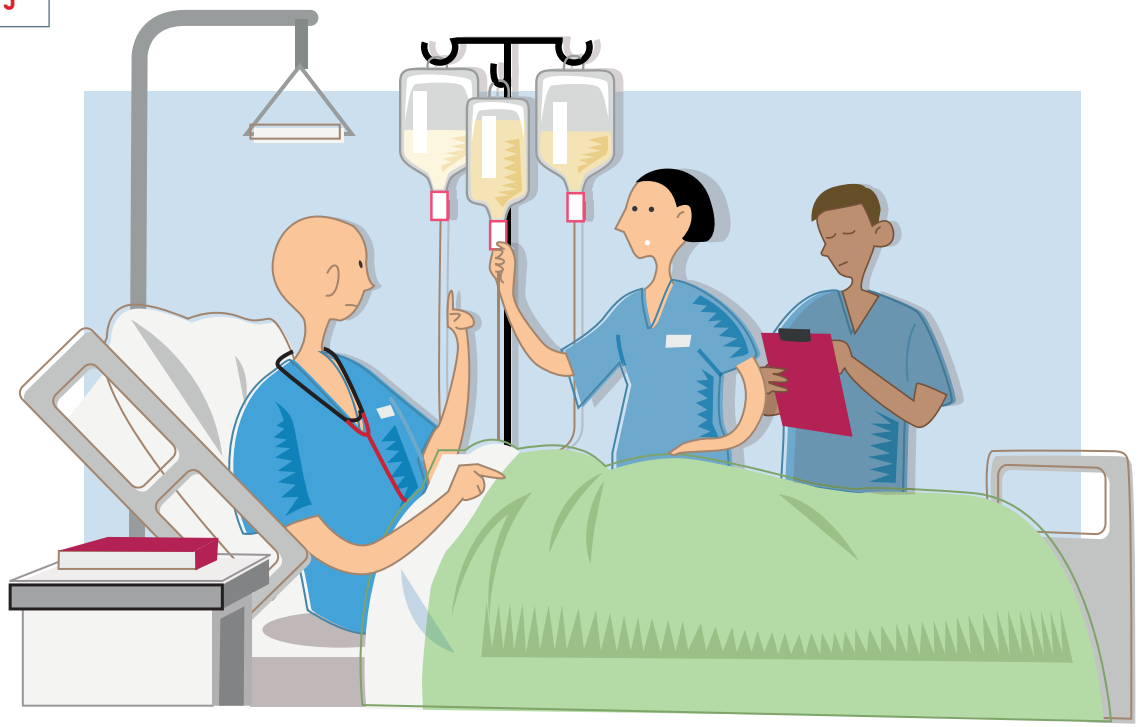
Patients come to clinicians not only bearing a disease, but also with illness in the context of a life. Cancer clinicians are expected, and indeed strive, to provide compassionate care. While clinical situations are often complex, lives also can be complicated to sort out and understand. Clinicians rely on their observation skills, their intuition, and their knowledge of healthy coping mechanisms, and they engage patients in meaningful conversations during which they learn about individual sources of strength, the extent of patients' suffering, and their fears and concerns.

Caring for colleagues is no different from caring for any other fellow human who needs attention and care. Undoubtedly our relationships are multifaceted, and we may be reluctant or only too eager to share personal stories with patients with whom we once worked side by side. Each person and each relationship is unique, and what matters is that we are fully present and engaged, or that we recognise we are unable to provide the necessary care and we step aside and ask for assistance. When caring for a colleague with whom we have a long-standing relationship, there may be an immediate level of empathy; we share the community in which the crisis happens. This relationship has to be developed with patients we are meeting for the first time. The compassion of strangers is created by exploring different pasts and different futures (at least initially) and opening a connection in the present.

Transitions, abandonment and empathy

Patients expect empathic caregivers in cancer care. We connect at an extremely vulnerable time, that requires "human and humane responses to [their] plight," to quote Ken Schwartz. Empathy is showing that we understand the patients' experience and how they feel, respect the gravity of it, and will not abandon them through it. Empathy has recently captured our attention as neuroscientists have mapped out the neuronal circuitry that mediates these complex engagements[5]. Empathy consists of affective, cognitive, and behavioural components, requiring patience, curiosity, and an ability to imagine oneself in the patient's shoes (perspective taking). Halpern wrote that empathic communication makes patients more forthcoming about their concerns, leading to stronger connections with caregivers[6]. Clinical empathy has been described as emotional labour, a powerful metaphor that alerts us to the effort involved in caring[7].

Empathy fluctuates during medical training, with a dramatic drop occurring in the third year of medical school[8]. The empathic 'reservoir' may be depleted as a result of intense experiences, over-reliance on technological aspects



of care, lack of mentorship, and organisational pressures and demands. Empathy appears to be regulated by perspective taking and by cognitive appraisal, and when it is absent, the focus of the interaction is on target organs or test results instead of on the whole patient. This is not simply a moral or philosophical issue, but one that can immediately and significantly impact patient care[5,7]. Empathic physicians take better patient histories and develop trusting and solid relationships with patients. Some studies have also shown that this connection has favourable effects on adherence to treatment, boosts immune function, and improves satisfaction with care, but others have failed to show any favourable effect on hard outcomes[5,9]. However, a recent study of audiotaped encounters between patients and oncologists gives us reason for pause and concern. Pollak and colleagues reported that oncologists only responded empathically to emotional revelations 22% of the time. Empathic responses were more common in younger, and female, oncologists. The authors commented on the "missed opportunities" and the failure to recognise and respond empathetically to emotional patient cues in the setting of a clinic visit[10].

Although we lack hard evidence to quantitate the benefit of healing connections, we hold them dear and aspire to experience them for ourselves and provide them to our patients. Perhaps novel scientific tools will assist us in researching and obtaining quantitative and qualitative data on biomarkers of compassion and empathic engagement that will serve to model clinical skills for future clinicians. Until such time, we rely on cultivating self-awareness, mindfulness, and reflection in our trainees and ourselves and look to role models for clinical guidance.

Conclusion

Caring for a fellow staff member is a wonderful privilege. Being the 'go to' clinician whose opinion is sought out and valued is a huge responsibility. Intrinsic in these roles is a greater responsibility to practice respectfully and professionally. Accomplishing this goal requires emotional intelligence and social dexterity to accommodate the nuances of each patient encounter. Insight and empathy are needed to continuously reassess the strengths and weaknesses of patient-centred clinical relationships. Guarding the trust implicit in those relationships requires more social understanding than most medical trainees anticipate or seasoned practitioners give themselves credit for, but it is vital in meeting the expectations of our profession and our patients. ■

Details of the references cited in this article can be found at www.cancerworld.org