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Role of Kindness in Cancer Care

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Abstract

The wonders of high-tech cancer care are best complemented by the humanity of high-touch care. Simple kindnesses can help to diffuse negative emotions that are associated with cancer diagnosis and treatment—and may even help to improve patients' outcomes. On the basis of our experience in cancer care and research, we propose six types of kindness in cancer care: deep listening, whereby clinicians take the time to truly understand the needs and concerns of patients and their families; empathy for the patient with cancer, expressed by both individual clinicians and the care culture, that seeks to prevent avoidable suffering; generous acts of discretionary effort that go beyond what patients and families expect from a care team; timely care that is delivered by using a variety of tools and systems that reduce stress and anxiety; gentle honesty, whereby the truth is conveyed directly in well-chosen, guiding words; and support for family caregivers, whose physical and mental well-being are vital components of the care their loved ones receive. These mutually reinforcing manifestations of kindness—exhibited by self-aware clinicians who understand that how care is delivered matters—constitute a powerful and practical way to temper the emotional turmoil of cancer for patients, their families, and clinicians themselves.

> *When I arrive at my appointment, I am greeted by the ladies of the front desk with a knowing smile… They made that effort to know my name. It seems so inconsequential… but it is my first interaction of a very long day… The moment I walk into your building I feel safe. I know I am surrounded by people who care.* (A letter to a cancer center president from a patient with cancer.)

Cancer care is a high-emotion service, which is characterized by a lack of customer control, feelings of powerlessness, severe consequences if things go wrong, high complexity, and long duration. Atypical levels of stress, worry, and fear are common.[1]

Simple acts of kindness can help to diffuse negative emotions, as the letter from the patient with cancer describes. Accurate diagnosis and treatment are paramount, of course, but how the care team delivers care also matters, as it can be a potent antidote to patients' negative emotions and may improve their outcomes.[2-9]

Kindness may be defined as "purposeful, voluntary action undertaken with sensitivity to the needs or desires of another person and actively directed toward fostering their well-being or flourishing."[10] Treating patients and their families with kindness by getting to know them, empathizing, listening, and responding to their needs earns their trust.[2,11-13] Kindness is similar to term "emotional care," used by Di Blasi et al,[13] whereby clinicians use warmth, reassurance, and empathy to reduce fear and anxiety. In discussing the delivery of care—especially cancer care—we prefer the term kindness for its simplicity, breadth, and familiarity. Emphasizing kindness highlights the need

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to complement the wonders of high-tech care with the humanity of high-touch care, especially for seriously ill patients.[5,14,15]

Although clinicians likely view kindness as a requisite component of providing cancer care, a number of stressors may interfere with their good intentions. The complexity of health care delivery systems, coupled with financial and institutional pressures, can create a barrier between clinicians and the care they wish to provide. Indeed, the care itself can be a barrier, as compassion fatigue is well described in providers who are routinely involved in emotionally charged conversations.[16] This reinforces the need to recall the integral role of kindness for both the patient and the provider so that it may be successfully, reliably deployed despite the pressures of the work. We propose six types of kindness in cancer care developed from our experiences treating critically ill patients with cancer (R.A.C.) and other life-threatening diagnoses (R.L.A.A.); being hospitalized for months with critical illness (R.L.A.A.); conducting field research at 10 cancer centers, a hospice, and a community health center, and interviewing approximately 400 adult patients with cancer, family members, and oncology clinicians and staff (L.L.B.); and studying operations at several pediatric cancer centers and interviewing patients' family members (T.S.D.).

TYPES OF KINDNESS

Deep Listening

Kindness requires listening intently to patients and family members, with minimal interruption, to draw out their preferences and feelings. Being truly present during the encounter demonstrates respect and fosters trust. Unhurried deep listening may seem incompatible with today's financial and productivity pressures, but its practical value outweighs the hidden costs of not listening well: Providing undesired treatment, missing information that is pertinent to the treatment plan, not recognizing patients' and families' lack of understanding, and thwarting clinicians' desires to better serve patients.[17-23]

Abraham Verghese cautions that the electronic medical record can impede deep listening: "The representation of the patient in the electronic medical record (the iPatient, as I call it) is necessary. But being with the iPatient too long is a guaranteed way of *not* being present with the actual patient."[24(p1926)] Deep listening shifts the paradigm from asking a patient, "What's the matter?" to inquiring, "What matters to you?"[19] A hospice nurse said, "We cannot be afraid of the deep conversations with patients to find out what's important to them, which you are not going to get by asking, 'How are you feeling today?'" (Unattributed quotes are the voices of interviewees.)

Deep listening is especially important in end-of-life care. A patient who was treated by one of us (R.A.C.)—a frail, elderly man with advanced lung cancer for whom additional aggressive treatment was futile—had a lifelong dream of making a family pilgrimage to Mecca. Discussion with the patient included moving from active treatment to improving quality of life, as well as the dangers of a strenuous journey versus missing a last chance to fulfill a dream. Bolstered by practical advice and family support, the patient journeyed to Mecca and returned. Although he lived only another 3 months, he and his family treasured this fulfilled wish.

Simple, open-ended questions can invite patients and families to offer otherwise undisclosed information.[3,25,26] Intensive care unit nurses at Brigham and Women's Hospital (Boston, MA) begin their shifts by asking patients, "What's the most important thing we can do for you today?"[27] Palliative care physician Susan Block engages patients in difficult conversation with questions, such as "What do you understand your prognosis to be?"; "What are your concerns about what lies ahead?"; "What trade-offs are you willing to make?"; "How do you want to spend your time if your health worsens?"; and "Who do you want to make decisions if you can't?"[28] An oncologist observed, "Healing conversations are part of the healing process."

Shared decision making is stymied if patients or their families discern from a clinician's rushed manner that he or she lacks the time to fully involve them. Weighing available—sometimes convoluted—care options requires sustained focus to address all of a patient's and family's concerns. Parents of a child with cancer noted: "We were given two options, both with significant drawbacks and perils. We talked with our care team in detail about our fears and hopes. At no point did we feel rushed, and that made us feel free to share our concerns…to work together to decide on the best plan. As parents, we needed to be able to live with our choices regardless of the outcome."

Empathy

Nursing scholar, Theresa Wiseman, has identified four essential attributes of empathy: seeing the world from somebody else's perspective, avoiding judgment when assessing a situation, recognizing the emotion present, and responding to

that emotion in a genuinely caring way.[29] Empathy represents an anticipatory kindness after honestly assessing the patient's situation and potential stressors and, in many ways, is actionable.

Any serious illness confers suffering, but a care team can mitigate avoidable suffering by understanding the emotion that diagnosis and treatment evoke, then injecting kindness.[30] At Australia's Peter MacCallum Radiation Center, providers recognize that cancer treatment can be traumatic, especially for children; therefore, they use creative solutions to reduce anxiety from the outset. For example, pediatric patients and their siblings may select from a catalog a superhero costume that they may choose to wear to appointments, and are invited to star in their own superhero action movie that is professionally filmed onsite at Peter MacCallum. Clinicians at Peter MacCallum also individualize care by recognizing patients' unique fears and anxieties. One parent recounts, "My son had general anesthesia for radiation therapy, but as he felt a lot of anxiety about this procedure, the team would allow him to sit on me during anesthesia. They also noticed that when he woke up, he got upset about lacking a shirt. Now the team puts his shirt back on before he wakes… To me, these small acts were the ultimate kindness, reducing his anxiety and distress and, therefore, my own."

A cancer surgeon told this story about a gay patient who was married to his partner: "I expected to have to remove his testicle. I asked if he would want to save sperm before the surgery… That conversation was incredibly important to him and very satisfying to me. Because of his cancer, he was allowed to be seen as a whole person and not a gay guy with a partner. He said, 'You are the first person who ever talked to me about that.'"

Operationalizing empathy may seem counterintuitive. We may envision empathy as effortless, graceful compassion that flows unsolicited from innately kind people; however, reliably delivering empathic care within an organization means embedding it in the culture, just as protocols for the safe administration of medications are embedded. At Henry Ford Hospital in Detroit, MI, oncology fellows are trained in empathic communication by improvisational actors who play the roles of patients and family members. This situational teaching shows physicians how to decode certain behaviors as emotional cues and practice responding empathically. The training's success reveals that the vital components of empathy—recognizing and responding to emotion—are teachable.

Generous Acts

Kindness often manifests as generous acts by individuals and institutions. Generosity contributes to a service organization's success because it strengthens trust-based relationships with employees and customers.[31] Generous staff put discretionary—extra—effort into their service of others.

In a study of adult patients with cancer, one of us (L.L.B.) asked interviewees, "Can you think of the best, most meaningful service experience you had as a [patient with] cancer?" Many responses, including this one, epitomized generosity: "My surgeon did something quite wonderful. She said, 'I am taking notes for you because it is hard to remember everything.'" Another patient said, "On several occasions, doctors have called me over the weekend to check in, just to see how I was doing."

Generous acts can strongly affect patients and families. A patient with bladder cancer praised a postsurgery nurse who taught him the best way to get out of bed at home. Patients at Marin Cancer Care extol the foot massages that are offered during chemotherapy. Staff at Northwell Health Monter Cancer Center refused to be evaluated by a patient copay-collection metric, which they felt conflicted with working to create a shame-free environment for uninsured patients and those who were behind on payments. A surgeon described a patient "who swears my 2-minute hug saved her life."

The annual employee giving campaign, "You and I," of Integris Health System reports cancer as the most popular donation choice since the campaign's inception. The Integris Cancer Institute has used the funds to support patient exercise through "Survivor Fit" and to provide free, nutritious meals to patients and families at the start of treatment through "CanServe." The newest program provides lodging assistance for those who travel to get treatment.

Generous acts not only benefit patients and families, but also the employees who perform them. Organizational generosity builds pride and creates a happier, more engaging, and less exhausting work environment.[2,32-34] Personal generosity can be immensely satisfying, renewing, and energizing.[35]

Timely Care

Heightened emotions upon a cancer diagnosis are likely to intensify the need for prompt action. Delays in setting clinical appointments, starting treatment, or receiving test results can be excruciating and can lead to dissatisfaction with the service and severe emotional strain.[1,36-38] An oncologist commented that, "Uncertainty is the issue. Patients want to know what will

happen to them and what treatments they will get. The sooner we can give them the information they need, the more they can calm down." In interviews (T.S.D.), parents of children with cancer would often remark that being in limbo is unbearable—it heightens the feeling of being powerless. Once a treatment plan is underway, a routine develops, which greatly reduces stress and anxiety.

A cancer center senior administrator commented that, "Every cancer center has a wait-time challenge; however, we can do much better on what we control, such as running our lab on time. Everyone must go through the lab. If the lab runs late, the whole thing goes late." It is the part of timely care that can be controlled that connects to kindness. Timely cancer care, in part, is a function of empathy and extra effort—it is a personal and institutional commitment to reduce patients' anxiety related to needless waiting for information or next steps.[39] Consider this patient story:

> In post-treatment, I was experiencing more fear than with the initial diagnosis. I had positive outcomes from chemo and surgery, but was really frightened on follow-up visits that something would show up. Lying on the [computed tomography] table, I thought, "Boy, they sure are taking a lot of pictures." Before one follow-up exam, I was especially upset. About 5:30 the evening before seeing the doctor, he emailed me and said, "All the images looked fine." It was a huge relief.

Opportunities abound for cancer practices to improve the timeliness of care. Some centers are investing in them, despite the upfront costs that may not be recouped and the disruption of change. These opportunities include:

- An institutional commitment to provide newly diagnosed patients, within 10 days, a care bundle that, although customized, includes a standard set of getting-started services.[39]
- A multidisciplinary clinic day when a newly diagnosed patient meets with each care team member to discuss the treatment plan and leaves with set appointments.[1,40,41]
- A cancer urgent care clinic that is open during off hours.[1,42]
- An off-hours call center that is staffed by experienced nurses who have access to the patient's medical records and can answer questions, make clinical appointments, and, if indicated, dispatch a clinician to the patient's home.[43,44]
- In-home medical and palliative care services.[45-47]
- An assigned patient navigator as a dependable direct contact.[48-51]

Enabling patients to receive information and services remotely—when clinically appropriate—is an important opportunity. Telemedicine and other remote services can transform the location and often shorten the time to nonsynchronous service. Kaiser Permanente's Northern California practice offers more than 100 Internet, mobile, and video services.[52] Some would not fit cancer care, but many, such as online symptom reporting,[53-55] lessons accessed from an eLearning Web site,[56] and scheduled telephone and videoconference visits,[57] could help patients with cancer receive more timely, effective care.

Gentle Honesty

"Cancer is a high-potency word, a word without any positive associations," states a patient with cancer. Most patients remember the moment they were told they had cancer. What clinicians say and how they say it can influence treatment decisions and patients' quality of life. No single message works for everyone. Asking patients how much they want to know about their illness is informative and kind.[3,58] Most patients want to hear the truth in honest, well-chosen words that convey a sense of partnership and that guide them to the right decisions.[11,58,59]

An oncologist comments that, "Far too often, patients and doctors are too optimistic. Realism is needed so that patients and their doctors can make good decisions." Another oncologist described this conversation as follows: "The patient would probably live a couple of more weeks, and another doctor wanted to do more [chemotherapy]. I told the patient, 'What I see is there is no more benefit from continuing [chemotherapy]. It is time to focus on day-to-day comfort. I think you'll live longer and better if we do that.'" A nurse practitioner said, "A doctor may say, 'We can continue treatment or we can just do supportive care.' We have to take the word 'just' out of that sentence."

When asked in interviews to identify words or phrases to never use with patients, virtually all oncology clinicians came up with one or more never words—for example, "You failed chemotherapy," or "You are lucky it is only stage II." Cancer practices would benefit from staff discussions of such words, with an eye toward banishing their use.[60,61]

Oncologists face complex internal pressures—giving patients every chance to live—and external ones—for example, patients or family members who do not want to give up.[62,63] Such pressures are inherent in cancer care and can make

gentle honesty and sensitive language ever more crucial. Although patients with cancer initially hope for cure or remission—focused hope—clinicians can guide them to another kind of hope when the disease is advanced and cure or remission is improbable. Intrinsic hope involves living in the moment for a good day of family love, positive reflection, perhaps a grandchild or a dog on one's lap, and well-managed pain.[17] The principal investigator of a US national clinical trial for adult acute leukemia describes "the peace, the comfort, the joy, and the sense of completion when a person chooses to live unencumbered by the demands of modern medical therapy."[64]

Support for Family Caregivers

Patients often lean on family members for emotional and physical support, help with medical activities, and assistance with daily needs.[43] Activities include going to doctor visits, preparing meals, visiting or staying in the hospital with the patient, administering medication, and organizing complementary therapies. It can also mean helping a loved one cope with fear, sadness, and anxiety. Family support and encouragement often motivate patients to participate willingly in self-care activities; however, caregivers themselves require support to maintain their own well-being.[43] Kindness in health care must extend beyond the patient to the family and other caregivers, especially when the patient depends greatly on those people. Supporting family caregivers in a role they often are ill prepared to perform—both cognitively and emotionally—bridges kindness and practicality. Cancer requires considerable informal care where patients live. Research has documented the benefits of preparing, empowering, and assisting family to provide care to a loved one.[65,66]

Johns Hopkins Cancer Center offers an annual off-site, 3-day weekend retreat for women with metastatic breast cancer and their partners, typically a spouse. Free of charge, volunteer staff engage attendees in open, safe group discussion on how partners can support those dealing with stage IV breast cancer, resources for coping with the disease, and end-of-life care. One of us (L.L.B.) observed the retreat and witnessed participants bonding with one another and with staff. This program epitomizes the true meaning of kindness in cancer care.

Whereas a programmatic approach to kindness has the potential to affect many, simple individual acts can be equally powerful. One of us (R.L.A.A.) who was cared for at Henry Ford Hospital recalls how meaningful it was when radiology technicians acknowledged her husband's fatigue. "Seeing him sleeping at my bedside each morning of what was a very long [intensive care unit] stay, they would gently cover him in a leaded apron when they shot my X-ray, rather than disrupt his sleep. That silent awareness of his needs was so simple, and yet meant everything to us. It meant his suffering was seen."

CONCLUSION

Kindness can be a life vest in a sea of suffering. Yet in delivering high-emotion cancer care, kindness can be lost to the intense pressures of too much to do in too little time. Our article proposes that there is an authentic efficiency in care embedded in acts of kindness. Unwise treatment—and its human and financial costs—can be avoided when patients are carefully listened to and gently guided in honest dialogue; family caregivers can help shoulder some of the clinician's burden if they are properly supported and prepared. Empathetic and generous behaviors can be meaningful, not only to patients and families, but to clinicians and other staff as well. Research demonstrates that compassion for others buffers stress.[8] The nurturing environment created by extending kindness to others, including coworkers, improves provider well-being and can be a potent antidote to physical and emotional exhaustion and burnout.[16,23,32]

Creating an organizational culture of kindness is the responsibility of everyone. In addition to background and skills, managers need to make hiring and promotion decisions on the basis of candidates' humanistic values. Chaplains, social workers, and others need to gather staff periodically to openly discuss the stressors in oncology work and to share their stories of loss, learning, and renewal. Senior leaders need to strengthen job engagement by investing in sustainable workloads, formal curriculum on such subjects as mindfulness and self-awareness, and meaningful recognition and clinician choice and autonomy, among other investments.[16,23,67,68] Individuals also need to support one another with kindness; even the simplest acts of kindness can make a profound difference, not only during the moments in which they occur, but in strengthening an organization's culture.

The personal stories of patients, families, and clinicians illustrate the impact of the human touch in cancer care. The six types of kindness—deep listening, empathy, generous acts, timely care, gentle honesty, and support for caregivers—are not mutually exclusive. Instead, they represent overlapping manifestations of genuine kindness, a powerful and practical way for clinicians to temper the emotional turmoil of cancer. JOP

Authors' Disclosures of Potential Conflicts of Interest
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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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