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Editorial

Communication in cancer care: An ongoing knowledge translation challenge



Patients and their families fully understand the importance of excellent communication with their professional health care providers as they progress through a cancer journey. In venues in which cancer patients, family partners, and cancer care advocates have an opportunity to express their perspectives, communication is inevitably noted as one of their high-priority concerns. And for decades now, there has been an ongoing and robust body of available scholarship, including nursing scholarship, directed toward trying to understand and resolve the unmet needs patients have in this regard.

My own interprofessional research team spent 15 years trying to dig into the complexity of the problem that communication in cancer care represents. Through a series of primarily qualitative studies, many including longitudinal tracking of changing needs and preferences over time, we were able to learn a great deal about what was important to patients and their families, why it was important, and how both good and poor communication practices influenced their experiences and outcomes. Here I will summarize the highlights of what we learned in the course of those studies, how we came to understand the nature of the challenge, and how we ultimately came to interpret the significant systemic barriers that remain in place with respect to taking these evidence-based insights into improving practice. By reflecting on what was learned, and why it has been so difficult to put that learning into action, I hope to encourage all oncology nurses to understand what their part might be in a difficult, complicated, but incredibly important contributor to the cancer experience of all who come under our care.

Insights from the qualitative evidence

The general style of our series of studies (funded 2001 through 2014) was interview-based listening to a diverse set of cancer patients' stories across a wide range of tumor sites and disease stages, and documenting what we could learn about how the features of their cancer and treatment contexts, as well as their life stage and social circumstances, shaped the issues that arose for them with respect to cancer care communication. We specifically asked what they had found helpful and unhelpful about the health care communications they encountered during their cancer care. We encouraged them to share examples to illustrate what they meant and to reflect on what they had learned that might be of benefit to future cancer patients. Given the diversity that is cancer, and the fact that so much of the 'evidence' that is taken up in making changes in oncology practice is presented with very large samples, we used larger samples than is usual for qualitative studies so as to try to substantiate our findings for the intended wider oncology audience. Our team was multidisciplinary, including oncologists, to ensure that our findings were not regarded as an unfair nursing critique on medical practice. And we

continually consulted with both patient and clinician advisory committees along the way to ensure our interpretations of the data rang true to their understandings and experiences.

What we clearly learned from patients was that communication in cancer care has the power to cause harm and also to nurture healing. Patients fully appreciate the complexity of cancer care, including the need to convey complicated information or break bad news, and the urgency of certain kinds of decisions. They also know the time pressure under which all of our cancer care systems operate,¹ and the challenge that clinicians have in providing certainty where the actual outcome for any individual patient is often inherently uncertain.² Nevertheless, throughout our studies, they told marvelous stories about ways in which their professional health care providers communicated with them in a manner that preserved clarity, supported their dignity, and/or helped them sustain hope. And they also told stories that demonstrated ways in which the communications they had encountered along their cancer care trajectory had caused them pain, whether in the form of unnecessary levels of fear and anxiety, eroding their sense of trust in the system, or feeling that their personhood had no place in the dehumanized machinery of cancer treatment systems.^{3,4}

While every patient had an individual story, there were clearly identifiable patterns in their accounts—aspects of their care for which they were in considerable agreement about how patients ought to be treated by the professionals involved in their cancer care. Universally we heard that people had a need to be 'known' within the cancer care system—to feel that they were making human connections with those providing their care.⁵ We found that the information provided to them in the form of statistical probabilities was often the most difficult to manage—to interpret how what occurred for proportions of patient populations might apply to their own single case. While they might not remember in vivid detail all of what was explained to them in a clinical consultation, it was often the numerical information (35% chance of a cure; 6 months to live) that became intrusive and anxiety-provoking in their thoughts. And we repeatedly heard stories about hope—not about a desire for unrealistic hope, but about an abiding wish to be supported in what it was that they could actually hope for, whether that be toward a cure or a quality of life for the time they had remaining. Even those patients whose self-described preference was to be realistic and pragmatic about their survival chances were rarely willing to tolerate communications that felt hope-destroying.⁶

Over all those years of interviewing, we learned about the importance of human diversities and their implications for understanding communication needs and preferences. Cultures, faith traditions, past traumas, family stories, social positionings, belief systems that did not fit the dominant norm all became occasions for heightened misinterpretation

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and misunderstanding. However, where they were respected and integrated into care processes and interactions, they could alternatively become a focus within which to feel supported. We also learned a lot about how patient communication needs and preferences often evolved and changed over the course of the cancer trajectory, so the person you may have interacted with six months ago is not the same person you have before you today.⁷

And beyond those common patterns, we heard about so many individual uniquenesses that could make patients vulnerable to communication problems, but could also be valued as points of connection. Indeed, across all of the stories people shared about their communication experiences, we came to appreciate how very important it was for people that they be seen as an individual—someone with a unique life, distinctive hopes and dreams, and particularized choices to be made. While most patients did not claim to understand the clinical science—they trusted that their clinicians had access to the best of current practice knowledge—they did expect that the science would be applied to their unique and distinctive clinical and personal situations. Therefore, feeling seen by their care providers and decision-makers afforded them a great deal of comfort that their own unique circumstances would be featured in the equation of recommendations for the best approach forward.⁵

With all of these insights about commonalities and diversities, we came to fully appreciate why standardized communications—such as those often taught in cancer communication training sessions—provide limited value in actually resolving the communication problem patients continue to face. Even within the ways of communicating that are generally seen as constructive, and helpful, there will be cases and contexts in which these tried and true approaches miss the mark, leave an undesirable impact, or potentially cause harm. So rather than trying to add to the communication ‘best practices’ literature, we turned our analytic lens in another direction.

Translating communication evidence into practice

After analyzing all of our data sets across the full set of studies, we came to a way of thinking about the cancer communication challenge that was potentially much more helpful than the “more communication training” that has been the ubiquitous recommendation arising from the vast majority of research reports in this field. Instead of attempting to articulate a universally applicable ‘best practice,’ we reasoned that explicitly developing an understanding of ‘poor practice’ from the patient perspective might allow for more creative approaches that actually stand a better chance of improving practice. Toward this end, we identified three very distinct categories of communication errors or injustices, each leading to different solutions.⁸ The first was ‘ordinary misses,’ which patients recognized as the inevitable reality for even the best of clinician communicators when the stakes are so high, the emotions are so fraught, and the information is so complex. The solution to those kinds of errors is found in the ongoing socialization and maturation of practice skills, given awareness of their importance and a willingness to try. And although most patients encounter these, when they understand them as misjudgments within a reliably caring communicative practice, they seem highly forgiving.

A second category of communication error is the ‘systemic misunderstandings’ that come from a field of practice having prioritized a clinician or system lens, not listening to patients. And the solutions to some of those shared misinterpretations can be found in both the inclusion of patient/family advisory systems and in expanding the body of qualitatively derived patient perspective evidence. The more we come to understand both commonalities and diversities in communication needs and preferences across the cancer spectrum and our patient population, the better we can strategize individual approaches to best effect and avoid some of the potentially negative impacts of our established ideas and attitudes.

The third type of poor communication we heard about from patients is a phenomenon we called ‘repeat offenders’—a small (but highly

impactful) subset of clinicians whose persistent communicative approach becomes a particular source of distress for many patients. These are the individuals who, by virtue of disinterest or an emotional intelligence deficit, seem unwilling or unable to convey basic courtesy, compassion, or respect in their encounters with patients, or to try to meet their distinctive moments of need with dignity and understanding. Beyond the immediate anguish patients may experience following a difficult encounter with one of these clinicians, they often learn that they are not alone in having had such negative encounters and feel anger and distrust at a system that allows these clinicians to continue to inflict harm on patients. When the clinician in question is the patient’s oncologist, the stakes are high. And if that oncologist has been resistant to feedback related to communication, more education is unlikely to make a difference. As long as an oncology specialist demonstrates technical competence in cancer management, unless there is external pressure, such as litigation, that might place the institution at risk, it may be difficult for even the most courageous system leader to try to address the problem through personnel management practices or disciplinary action.

The kinds of solutions that may be needed include collective attention to structures and strategies to buffer the impact of the problematic communication and protect the patient. Nurses are ideally positioned in this regard, as they typically know which clinicians exhibit poor communication with their patients and the contexts within which patients are most vulnerable. If they value ‘communication safety’ as a basic right for all cancer patients in their care systems then they can begin to build a shared culture of intolerance toward problematic communications that cause harm. Bringing reports of such negative impacts to light, such as in interprofessional team meetings or rounds may prove helpful in galvanizing a sense of shared responsibility toward a collective response. Because such problems rarely resolve on their own without intervention, it may also be necessary to advocate for changes in usual practice, for example, ensuring that certain oncologists are not dispensing bad news outside of the presence of a skilled nurse, or that patients who are particularly vulnerable to the effects of such communications are flagged for focused nursing follow-up (debriefing) after consultations.

While it remains elusive to articulate exactly what communication excellence entails and how to attain it, the good news is that it does exist, and patients greatly appreciate it. And paradoxically, our most promising path toward making a meaningful difference is to aim our strategic skillsets directly toward exposing poor communication and applying our nursing wisdom to eliminate it.

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Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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