

Establishing trust through clear communication and shared decision-making

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In a related Humanities article — the first in a new series on trust in health care, authored by patients — Louis Lochhead describes how interactions with his wife’s caregivers in an intensive care setting undermined his trust that they were working in his family’s best interests.¹ As a practising intensivist, I felt uncomfortable and slightly ashamed on reading the article. I’d like to think the events described occur rarely, but I know that versions of the scenario described are common. People with lived experience have important roles within health systems, from monitoring and advising on the quality of care, to helping to set priorities for research and participating in the development of clinical practice guidelines. Lochhead’s article compellingly illustrates persistent gaps in how clinicians understand and fulfill our roles in shared decision-making, which I plan to try to bring to my own practice.

First, although clinicians, patients and their families often do have different values and preferences, this needn’t lead to a failure in shared decision-making — an essential component in patient-centred care. The physician’s role is to communicate information about the patient’s health condition and the different care options, including what is known about the advantages and disadvantages of each option and their prognostic implications. Ultimately, however, it is up to the patient or substitute decision-maker to choose the care plan that is most appropriate, given the patient’s values, preferences and goals. Substitute decision-makers must decide based on their understanding of the patient’s values and preferences, not their own. Patient autonomy, an important pillar of medical ethics, underpins this model of shared decision-making. Thus, clinicians must accept that a course of action that they suggest may not be accepted by the patient. The relationship between physicians and patients must be stronger than any difference in values and preferences, because abrogating the patient’s prerogative to decide on the basis of their values and preferences invariably erodes trust.

I have observed that the physician’s role as communicator in shared decision-making is often misunderstood despite its being explicitly described by the Royal College of Physicians and Surgeons of Canada.² Fulfilling this role begins with active listening and an exploration of the patient’s perspectives. Physicians are then expected to integrate what they learn through listening into the broader context of the patient’s reality and to seek a “common

Key points

- Clinicians, patients and their families often have different values and preferences, but this needn’t lead to a failure in shared decision-making.
- Maintaining meaningful communication, regardless of agreement, is the foundation upon which shared decision-making is built.
- Abrogating the patient’s (or substitute decision-maker’s) prerogative to choose their preferred care option, based on clear information and in line with their values, preferences and goals, invariably erodes trust.
- Goals-of-care communications should ideally include clear acknowledgment of scientific uncertainty and expression of willingness to revisit decisions in light of changes in a patient’s condition.

ground ... developing a plan to address [their] medical problems and health goals in a manner that reflects [their] needs, values, and preferences.”² Perhaps the recent reform of Canadian medical specialty training with Competence by Design³ will improve how clinicians implement shared decision-making, but it would seem important to ensure that this is indeed the case.

Second, Lochhead’s article underscores that small things make a huge difference. He clearly describes his unmet needs of regular communication with the clinical team in the intensive care unit (ICU). Evidence and guidelines support the tenet that even when clinicians and patients don’t immediately agree, and especially when they disagree, maintaining meaningful communication is the foundation upon which shared decision-making is built.⁴ A prolonged experience of critical care sometimes leads to reassessments of the goals of care. However, not everyone moves at the same speed, and patients should not be the only ones expected to adjust. I was struck by the impact on Lochhead of the ICU team’s failure to communicate the good news that his wife had regained consciousness. Health care workers in acute care settings usually communicate bad news promptly — for obvious reasons — but rarely do the same for good news, perhaps assuming that family members will enjoy the surprise or because they do not see

communicating good news as urgent, or they wish to be cautious. Yet withholding good news could easily be interpreted as a manifestation of the clinicians' "mauvaise foi" and unwillingness to change their minds. Importantly, evidence-based guidelines explicitly recommend "routine interdisciplinary family conferences to improve family satisfaction with communication and trust in clinicians ..." as well as the use of structured approaches to communications to include "... active listening, expressions of empathy, and making supportive statements around non-abandonment and decision-making."⁴

Third, improving the recognition and communication of scientific uncertainty is deeply important. Patient autonomy is obviously not without limits. For example, physicians are not expected to deliver interventions that are physiologically futile. However, physiologic futility is very narrowly defined as a situation where there is no possibility of biological efficacy.⁵ Futility implies absolute prognostic certainty, which is uncommon; therefore, experts suggest using other terms to communicate that some interventions may be "nonbeneficial" or "potentially inappropriate." Lochhead describes how experts in traumatic brain injury communicated to him a high degree of certainty that his wife's prognosis was hopelessly poor. Clearly, given the clinical evolution, this was misplaced. Predicting prognosis in patients with traumatic brain injuries is known to be difficult.⁶ However, medical uncertainty in general, whether it is about prognosis, diagnosis or treatment effectiveness, is probably under-recognized, and miscommunicated.⁷ Among the recommended structured approaches to goals-of-care communication, many include variations on the theme of describing scientific uncertainty, ascertaining mutual understanding and revisiting decisions in light of changes in the patient's condition.⁸

I applaud Louis Lochhead for writing about his painful experience to shed light on a crack in trust between clinicians and people with lived experience. I hope that *CMAJ's* new article type about trust in health care will offer clinicians an opportunity to learn from people with lived experience. That's how the light gets in.

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