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Editorial

A New Way to Listen to Patients: Heeding Patient Reported Experiences to Improve Quality of Care

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See article by Kemp et al., pages 1344–1352 of this issue.

Person-centred care (PCC) places the person first by providing care that is respectful and responsive to individual preferences, needs, and values and in turn guides all clinical decisions.[1] Although this may seem obvious, in reality most health systems actually require patients to adapt to and navigate an established structure, rather than listening to what patients have to say, and involving them in decision-making. PCC, when done correctly, improves the experience people have with care, encourages more involvement in decisions, impacts health outcomes, reduces the use of services influencing the cost of care, and improves the satisfaction of the professionals who provide the care.[1] PCC is achieved by integrating clinical data with both impartially collected patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Whereas PROMs are captured by standardized, validated questionnaires that can be either generic (such as the Short Form-36) or disease-specific (such as the Seattle Angina Questionnaire), PREMs examine how processes of care impact patient experience. PREMs are designed to be objective rather than subjective, but still manage to capture functional (eg, experience with the physical environment and hospital facility) and relational (eg, interaction with health care providers) information. Therefore, both PROMs and PREMs play critical roles in the evaluation and delivery of high-quality patient care. One of the challenges is how to collect these data broadly and yet inexpensively.

In Canada, administrative data, including those characterizing patient experiences, are collected through the Canadian Institute of Health Information, an independent, not-for-profit organization that provides essential information on Canada's health systems, and, more importantly, on the health of Canadians. Working with a range of stakeholders, including government, policy makers, clinicians, researchers, and the public, Canadian Institute of Health Information has prioritized the measurement of pan-Canadian health systems performance through the lens of the patient experience. This is done using a validated tool—the Canadian Patient Experiences Survey-Inpatient Care (CPED-IC).[2] Data can be collected by mail-out or telephone call, and the surveys are available in multiple languages. There are some shortcomings with the collection of the data, which are typical of surveys—not all people respond, and those who do may be healthier and less frail that those who do not.[3] Furthermore, there is a lag time of up to 6 weeks from discharge to data collection, which may lead to instances of recall bias. Nonetheless, these data represent a wealth of patient-centred information that has thus far not been widely used.

In this issue of the *Canadian Journal of Cardiology*, Kemp et al.[4] report specifically on the Alberta patient experience for cardiac surgery, using novel methodology. A modified version of the CPED-IC, which is administered in Alberta by telephone, was linked with corresponding inpatient administrative data records. While Alberta Health Services collects data on a random sample of eligible discharges, Kemp et al.'s study focuses on patients who had either coronary artery bypass surgery and/or valve replacement surgery at the 2 cardiac surgery centres in Alberta. In this study, the top performing questions (those reporting the most positive response options) included discharge planning, being treated with respect by the doctors and nurses, and the efforts of hospital staff to alleviate patients' pain. This is a credit to the cardiac teams at both institutions, whose efforts are clearly appreciated by the patients. Conversely, several areas for improvement were also identified. Not only do these not come as a surprise, but they have significant implications for patient safety and outcomes of care. Patients reported that they were often not informed about the potential side effects of new medications. This may be true; however, given the psychological and emotional stressors associated with cardiac surgery, the overwhelming amount of information being provided, and a delay in up to 6

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weeks for the CPED-IC survey, patients may also simply not recall receiving the teaching. Either way, this observation results in increased noncompliance and emphasizes the importance of continued patient education (with paper or web-based information provided for reference after discharge) and access to programs such as cardiac rehabilitation. Furthermore, it reminds us that given the geographic vastness of the province of Alberta, and indeed, our entire country, we need to learn to better support patients from smaller constituencies; new forms of cardiac rehabilitation may be an option.[5] Patients also reported that the hospital environment was too noisy at night. Rather than only being a nuisance, a noisy nocturnal environment can have serious detrimental effects such as increased risk of delirium and subsequent loss of function.[6] Finally, it was pointed out that bathrooms were not always clean. Once again, this can have major implications, not the least of which is the development of hospital-acquired, potentially drug-resistant, infections. Although cleaning up after ourselves has been ingrained in many of us since childhood, it is hard to do that when hugging a heart pillow to get out of bed and walking across the room is a major challenge early after cardiac surgery. The fact that this was a serious issue identified by patients suggests that all institutions should revisit training for both custodial and health care staff.

Despite the proliferation of patient experience surveys, there is a dearth of Canadian research in the area. In fact, while recognizing that patient experiences impact health outcomes,[1] health services research continues to focus on clinical endpoints such as 30-day readmission rates, mortality, and combinations of major adverse events, to date not including the impact of the self-reported PREMs as either predictors of outcomes or as endpoints themselves. The study by Kemp et al.[4] is a step in the right direction and is in essence the first rung on the ladder towards meeting the much sought-after triple aim (better health, improved experiences of care, and lower costs for the system) of health care in Canada.[7] Although the standardized collection of the patient experience is instrumental for improvements in PCC, the investigators have in fact provided a methodology for building a pan-Canadian patient-centred database required to drive improvement in various demographic, regional, and clinical cohorts in the Canadian health care system. Patients have been given a new way to speak; we just have to listen. Providing truly relevant, patient-centred care is dependent on it.

Disclosures

The authors have no conflicts of interest to disclose.

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