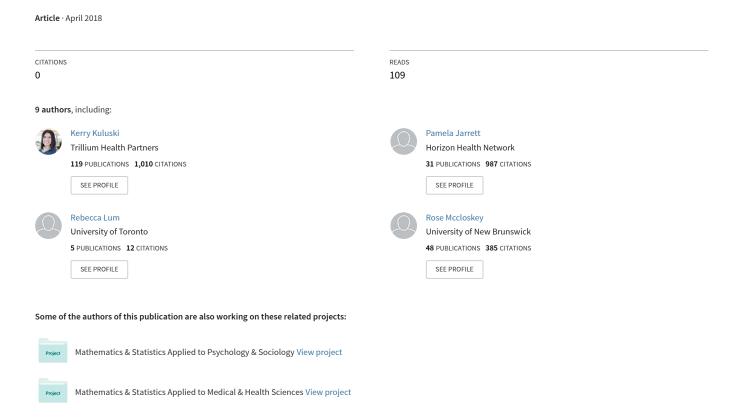
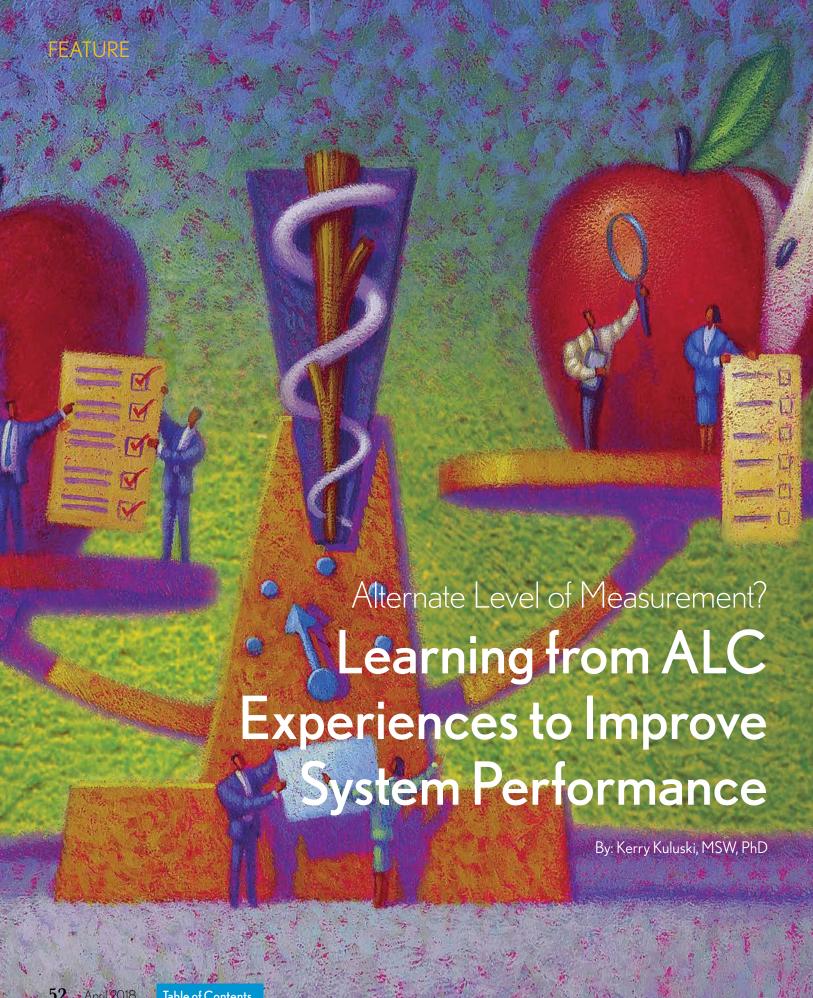
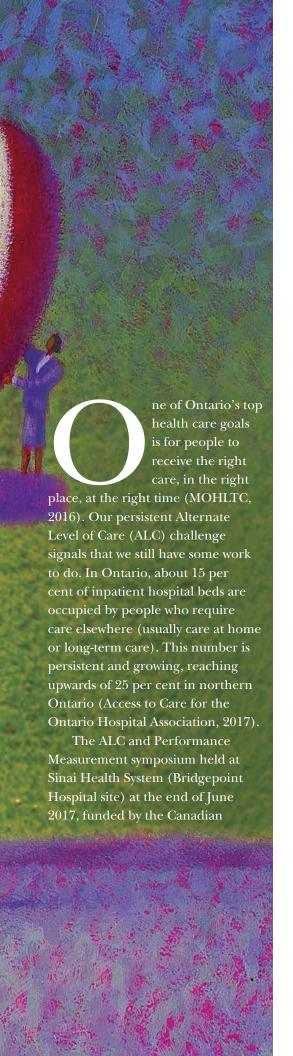
Alternate Level of Measurement? Learning from ALC Experiences to Improve System Performance







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Institutes of Health Research, provided a forum for stakeholders – providers, policy planners, patients, caregivers and data developers – to reflect on future directions to address ALC with a strong focus on measurement and personal care experiences.

At this symposium, Professor Jon Glasby, Head of the School of Social Policy at the University of Birmingham, referred to ALC as the "deep hospital". It refers to a phenomenon observed by those in the field: the deeper – or perhaps longer – a patient is in hospital, the harder it is to get out. What can we do to avoid the deep hospital?

As a start, we can look at the data we currently have to better understand the problem. In Ontario, Cancer Care Ontario's Access to Care branch provides real-time ALC data, including the numbers and care destinations of all ALC patients in acute and post-acute hospitals across the province. This data resource provides a huge opportunity for Ontario's health system to address the issue and develop a capacity plan. However, to truly understand how to build capacity in the system in a way

that works for people, we need to marry these data with people's stories, particularly the stories of people in the trenches of ALC: patients, their families and providers. Capturing their stories may point us toward person-centred solutions to the ALC challenge, which is another goal of Ontario's health system with the passage of the *Patients First Act* (2016).

Capturing Missed Opportunities to Intervene

At a health system level, we tend not to measure experience across settings or take into account the rather complicated, messy, cumulative or longitudinal experience of patients and caregivers. Despite its messiness, gaining a snapshot, over time, of this experience will help us see and understand these individuals within a broader context. Capturing this broader context is vital to identifying solutions to the ALC challenge that will work in the longer-term.

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Using a hospital admission as an example, we can ask: "What were the events leading up to the person's hospitalization? Why do they return to the hospital? What are the barriers to staying at home? How can we make it easier for the person and their caregiver in their day-to-day activities?"

While some organizations are already asking these questions, we still need a population-level stock of answers to these questions to make a stronger case for future health reforms. These questions will likely lead us outside the confines of the health care system and necessitate relationships with other sectors, such as housing, finance, transportation, and other community supports. They also inevitably bring us to the whole notion of prevention. Professor Glasby's research revealed that there were missed opportunities to intervene in the period of time before hospitalization that could have potentially made a difference with respect to prevention (Glasby & Littlechild, 2016).

Developing a holistic view of patients, rather than limiting this view to a single point in time, is necessary if we are to effectively address the ALC challenge. What we've learned so far from patients' experiences and Professor Glasby's research is that isolated initiatives are insufficient responses to such a complex issue. Any effective solution will take time, decisive action and collaboration across the system.

Measuring What Really **Matters**

Understanding patients' view of quality is essential to developing a performance measurement strategy and appropriate metrics that reflect this view. Measurement tools have preconceived assumptions of the things that shape a patient's experience and may (by virtue of the questions asked), miss aspects of experience that are important to people, and specifically in this discussion, contributors to the ALC challenge. While current measures tap into important elements of experience like the relational aspects of care (e.g., were you treated with respect and dignity?), we need to look beyond these elements.

The needs and priorities of patients and caregivers might not have anything to do with a particular health care service, a relationship they have with a provider, or a particular disease or symptom. Asking, "What are your goals?" and "What are you most afraid of?" could signpost where people's needs may be greatest. Postdischarge questions, such as, "Were you confused?" and "Were you given a number to call; if so, was it helpful?" are other questions that would signal communication breakdown, poor access to resources, and other areas that need attention.

The growing challenges with ALC can be viewed as symptomatic of a greater problem within the system as whole. By measuring what really matters to patients and caregivers, we have a better chance of arriving at the root of patients'

health care challenges. This, in turn, will help us identify what supports we can put in place as a system to enable more seamless care across the continuum, effectively address current patient and caregiver needs and ultimately reduce ALC.

Considering the Voice of Caregivers - Paid and Unpaid

Another critical consideration in any measurement and action strategy is to understand health outcomes, experiences, and costs for all types of care providers (both paid and unpaid).

When patients enter the system, do we document if they have a caregiver and what their capacity to care is? Do we consider how we can best support them (now and when the person they care for returns home)?

Unpaid family members and friends play a crucial role at all stages of the patient's illness, including care of the patient during the ALC phase (Kuluski, Im, & McGeown, 2017), and therefore, are an integral aspect of solving the ALC challenge. Moving past ALC and into post-discharge care is highly contingent on a caregiver's willingness and availability to continue to provide care and support. Ironically, they may be left out of relevant discussions (Jeffs et al., 2017).

Caregivers need to be formally identified, as they themselves may not call themselves, or recognize themselves, as caregivers. Caregivers

may have important questions about how to provide care (which can include heavy personal care), and how to seek supports for self-care. Caregivers often suffer from heath consequences (they can become patients) and endure large sums of out-of-pocket and opportunity costs. Greater understanding of how caregivers fit into patients' health care journeys cannot be overlooked if we are to effectively address the ALC issue. Providers can use this information to develop better supports for caregivers and also optimize the way the system interacts with them to enhance patient outcomes.

These strategies must be coupled with support for paid care providers. Similarly, we must ask, "How can paid providers be supported in their role to capture the patient and caregiver story and be resourced to respond?" It is easy to criticize the decisions and practice patterns of providers when we don't consider the busy and unpredictable contexts in which they work, which leaves little time for important conversations with patients and families.

Taking a Comprehensive View

The patient and caregiver voice can lend greater depth and understanding to a complex problem such as ALC. In attempting to capture their experiences and perspectives, we need to ensure that we are asking the right questions, and taking a more comprehensive view of their

circumstances which can impact their health, their ability to recover or maintain their health, and inevitably, their health outcomes.

In a system that is struggling with capacity issues due, in part, to an aging and growing population, we need to consider marrying people's lived experience with quantitative data, and perhaps we can introduce more thoughtful and enduring solutions to a longstanding challenge.

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