In Pursuit of Better Care Transitions: Lessons Learned from a Co-Designed Project

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Abstract

In this commentary, we reflect on our experience of co-designing an intervention to address challenges due to delayed hospital discharge (known as alternate level of care in Canada). Through a series of focus groups and co-design sessions, we identified common challenges with delayed discharge (including a lack of services while waiting for discharge and poor communication with the care team). In co-designing service improvements, we (1) amplified the voices of patients and caregivers, which helped them feel unified in their experience and (2) developed tools that aim to improve patient, caregiver and provider experiences. In this commentary, we reflect on these impacts along with the key lessons learned.

Key Points

- We co-created a strategy (i.e., components of an intervention) to address challenges with delayed hospital discharge (a care quality issue experienced by health systems worldwide).
- Starting at the very beginning of the project, shared leadership (i.e., shared power) among all stakeholders was essential to create a safe space to open up.
- Projects can lose momentum if participants do not stay connected to people (i.e., decision makers) who have the power to make the change required for the co-designed activity/intervention to be adopted and implemented.

Background

On June 11, 2018, a group of mostly strangers (a researcher, a patient and caregivers) met in the governor's tea room of the historic Don Jail (now Bridgepoint Hospital's administrative building) for the first time. Our group came together through a common interest: improving delayed hospital care transitions (referred to as alternate level of care [ALC] in Canada). Three years later, with an additional patient member, we are still going and eager to share our journey through this commentary.

Part One: The Evolution, Purpose and Impact of Our Work Together

It started over coffee (lead author's experience)

As a researcher fairly new to the patient engagement space, meeting my first caregiver partners was akin to blind dating. We met over coffee in a neutral, safe and comfortable atmosphere. They chose the place, and I met them there. These coffee chats were an effective way to meet, share and assess the next steps. Other patients/caregivers who would eventually join

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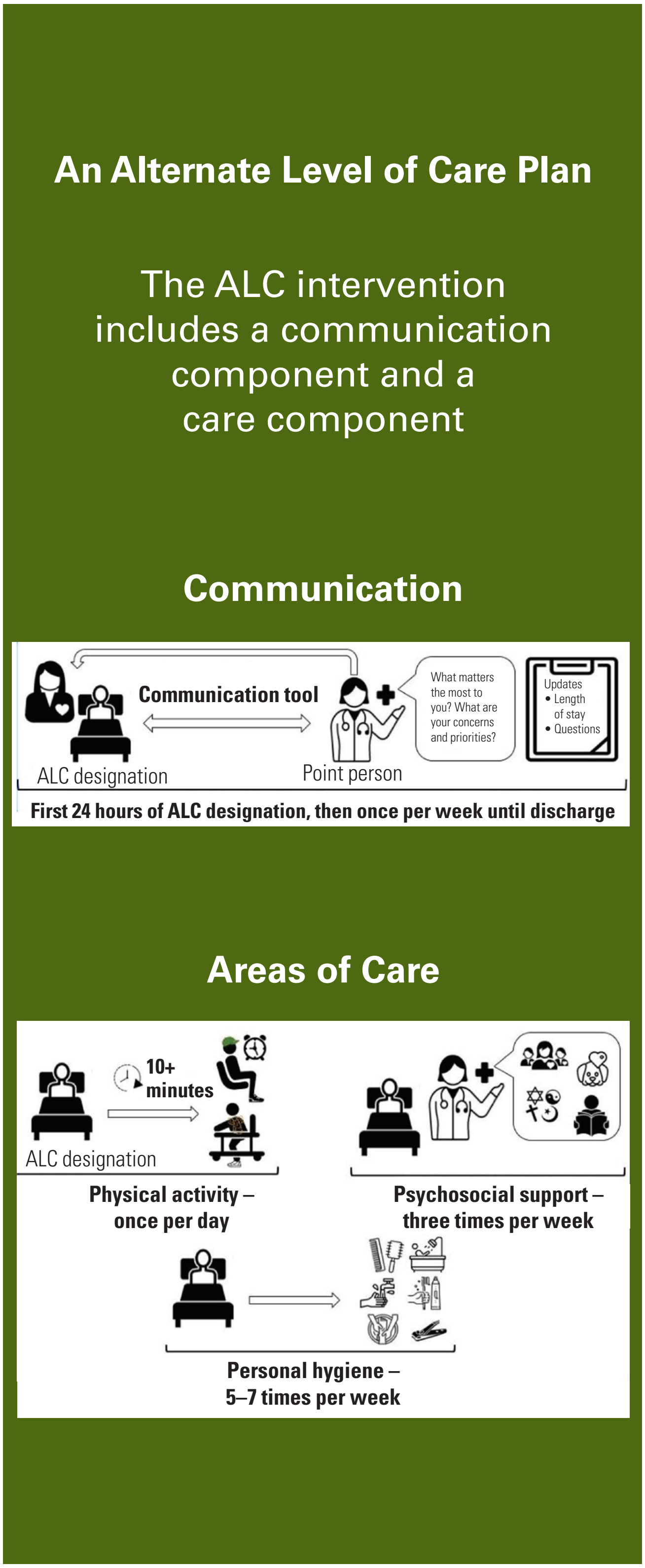
P = Patient or caregiver partner.

our council/team were already members of patient and family advisory councils at other hospitals. They responded to flyers shared in hospitals by members of a regional ALC task force (an initiative led by health system leaders who recognized that we needed to hear the voices of patients and caregivers). After a few council meetings, we identified the need to find another patient partner, and a hospital social worker introduced us to a current ALC patient who joined our team.

FIGURE 1.
Components of the ALC Intervention



We focused on improving delayed care transitions (i.e., ALC)

All patients and caregivers on our team had experienced a delayed care transition and wanted to see systemic changes. Care transition refers to moving from one sector of the healthcare system to another (i.e., hospital to home or to long-term care [LTC]). Sometimes, this transition in care is delayed (Walker 2011), resulting in negative personal and system-level outcomes. Transition delays (i.e., ALC) are experienced in hospitals worldwide (Amy et al. 2012; Challis et al. 2014; Costa and Hirdes 2010; Costa et al. 2012; Gaughan et al. 2017; McCloskey et al. 2015; Rojas-Garcia et al. 2018; Sutherland and Crump 2013; Tan et al. 2010). Across Canada, the number of beds occupied by ALC patients exceeds 13% almost daily (Sutherland and Crump 2013). ALC patients and their caregivers report a drop (or absence) of care and little communication about next steps. Patients experience functional decline (Bender and Holyoke 2018; Kortebein et al. 2007; McCloskey et al. 2014; Swinkels and Mitchell 2009; Wilson et al. 2014), patients and their loved ones experience confusion and stress (Cressman et al. 2013; Everall et al. 2019; Kuluski et al. 2017) and resources are not optimized (Burr and Dickau 2017; Ministry of Health and Long-Term Care 2019; Sutherland and Crump 2013; Walker 2011). Although the number of patients with an ALC status decreased during the first wave of the COVID-19 pandemic, ALC rates have fluctuated over time and are rising again (Howlett 2020; Roberts 2020; Sibbald 2020; Zeidler 2020). During the COVID-19 pandemic, outbreaks and concerns about safety and quality of care in LTC created an additional obstacle for safely transitioning people out of hospital (Grant and Ha 2020).

When our research team scanned the literature for strategies to improve these delayed transitions, we did not find any examples that were co-designed with patients, families and their care providers (Cadel et al. 2021). Our team of researchers, research staff, patients and caregivers came together to address this gap.

In an effort to co-design a strategy with patients and caregivers, we formed the ALC Patient and Caregiver Advisory Council. To identify key "pain points" during ALC, we conducted two focus groups (one with patients and caregivers and a separate one with care providers) and three co-design sessions with a mix of patients, caregivers and care providers across Ontario. Altogether, 61 people were engaged. We began our work in Toronto, ON, with funding from the Canadian Institutes of Health Research. Through the Ontario SPOR SUPPORT Unit (OSSU) Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach Award (EMPOWER), we expanded our co-design sessions across Ontario, and designed a website and a video to share our work on a wider scale. Council members' roles included creating terms of reference and other administrative activities related to council meetings, advising on project goals, sharing perspectives and, later, facilitating focus groups and co-design sessions. Rather than formally assessing the impact of working together, we held council meetings in between co-design sessions, allowing time to reflect on and revise our intervention (Figure 1). Together, we identified components of an intervention to improve the ALC experience, including a communication guide (a set of questions for patients, caregivers and providers to ask each other) and a care component (core set of services).

The impact of our work together

First impact: We amplified the voices of patients and caregivers

By being part of the council and project activities, patient and caregiver partners noted that they "felt less alone."

> [We had the] opportunity to speak and find out [about] other people [who] were in the same boat [allowing us to] build strength and overcome fears. (Lucy Bilotta, caregiver partner)

Ida McLaughlin, a caregiver and council chair, noted the importance of "bringing [patients and caregivers] to the table right from the start. [In doing so] you're more likely to have something that works, otherwise they [providers/leaders] come to the table with one-sided experience."

Lucy added that involving patients and caregivers is important because "patients and caregivers [are the ones] that have to live with the change."

> What strikes me, as a caregiver, is [that] we know the one we are looking after … but the healthcare people don't know what they [patients] like, what they don't like … Part of our job is to tell them. (Gordon [Gord] MacGregor, caregiver partner)

Ida reflected on the importance of being *beyond* her caregiver experience (her great aunt has passed away) and of having the ability to see the bigger picture: "I have watched patients and caregivers interact with hospital workers and have noticed that people are very emotional in the moment but here we are in a committee, and we can step back … Yes we bring our emotions to the table, but we can analyze things really clearly."

Gord, who shared his story in a podcast as one of our project outputs, said, "I really enjoyed doing the podcast. That was a big thing for me. Talking about my experiences and sharing them. I don't mind getting up and speaking to people."

The council still exists because of the members' commitment and desire to raise awareness on what ALC means and its implications.

> Nobody knows this is happening. You hear comments about hallway medicine … people think you are waiting a couple of days for a bed [but] it's more than that." (Ida McLaughlin)

Lisa Bennett added, "Other people are reaching out to me to learn more about my experiences and learn from what we learn from each other."

Second impact: We developed tools to improve patient, caregiver and provider experiences

In co-designing the communication guide, Lucy noted: "It opens a two-way street. Now we both have tools, not just providers."

Monika Syed concurred: [It is] "not adequate to keep what worked before. You need to get both sides. Having a group like this opens up the opportunity to change for the better [and] overcome roadblocks."

In addition, Lisa felt value in working in partnership with healthcare providers. She shared that by "having health professionals, you understand the other side of the coin," and it is "equally important to understand [their] obstacles." In reference to care providers, Lucy added, "Their hands are tied too. They only have the tools they have."

In reflecting on our co-designed activities with patients, caregivers and care providers across Ontario, Ida noted: "We've gone to others to verify that these are things that we've all gone through – common problems." Ida added that we can say that "these recommendations can help."

In addition to supporting patients and caregivers, Ida noted that addressing ALC issues could "free up a lot of beds."

As hospitals continue to deal with capacity issues (including ALC) and the COVID-19 pandemic, Lisa noted: "Now we've got two problems, and neither one of them will go away."

Alongside the above-mentioned impacts, our work together informed a set of leading practices for ALC for Ontario hospitals. For example, strategies to include patients and caregivers in care planning and decision making are part of the leading practices, along with our co-designed communication guide. The ALC leading practices will be circulated to hospitals across Ontario in the near future.

Part Two: Key Lessons Learned and Insights

Having accommodations in place so that no one feels excluded

To reduce barriers to participation in our co-design sessions, we offered accommodations for people with sensory impairments, medical needs and language barriers. We were also mindful about *where* we held the sessions. Our preplanning session with the council and an external expert facilitator in co-design helped us think through ways to engage people based on their specific needs and plan the sessions. During the co-design sessions, a volunteer verbalized steps of the co-design process and made notes on behalf of a council member experiencing blindness. We did not resort to traditional forms of knowledge sharing (Microsoft PowerPoint) and described any visuals we shared. We also hired an interpreter to work with a Mandarin-speaking patient during one of our co-design sessions. In-patient participation was made easier by holding focus groups and co-design sessions within three Ontario-based hospitals (Sinai Health System, Toronto; Health Sciences North, Sudbury; Trillium Health Partners, Mississauga). We kept sessions small (10–12 participants) and divided participants into smaller groups for deeper discussions. Also, in providing honorariums, we considered impacts on participants' financial circumstances (i.e., we divided payments between fiscal years).

One limitation of our project is that we just scratched the surface in terms of our attention to equity and diversity. While the council itself has a mix of men and women from different social locations and with experiences related to living with disability, only one of our members and a few of our co-design participants were from visible minority groups. Moving forward, development of approaches to engage a more diverse group of patients and caregivers and attention to race, gender, ethnicity and other social factors and how these shape co-design strategies will be essential.

Deliberately sharing leadership

The term *sharing leadership* is what the council members chose to use instead of the concept *sharing power*. The first step of shared leadership is giving people the space to talk. At our first meeting, we set the foundation by each council member sharing their story – from Gordon's wife, who was stuck in hospital, battling mental health challenges to Ida's elderly aunt, stuck on a stretcher, frightened and confused, waiting for a bed to open up. Instead of coming to the table as a "know-it-all" researcher, I (lead author) admitted that working in partnership with patients and caregivers was new to me and that I was excited to learn and receive guidance from the group. I asked people to call me out if I engaged in "research speak." As a result of sharing leadership with patients/caregivers, we were able to design something reflective of their needs and experiences.

We had co-design sessions that were fully led by council members. Other sessions were co-led by council members and researchers. Patient and caregiver partners liked both formats. I (lead author) was worried about having council members in facilitation roles during co-design sessions as I had thought they might not be comfortable (which later turned out to be my assumption). From this, I recognized that I continue to be influenced by traditional conceptions of the "researcher as leader." I also learned that partnership need not entail handing all power to patients and caregiver partners; rather, it means sharing leadership (or power) in ways that work for everyone. As noted by a patient partner and council member, Murray Powell: "Knowledge and involvement of the patients in their care path is, in fact, power, and accommodating patient needs provides a means to that end."

Finding ways to capture more patient voices is important

Patient voices are critical but seldom captured in projects that focus on ALC. The switch to virtual council meetings and co-design sessions during the pandemic made it even more difficult to engage people while they are in hospital. We engaged a few patients through council and co-design activities, but caregivers were the main source of insights on both patient and caregiver needs. While it is possible to garner patient experiences through the caregiver, it is not the same; although, we must note that in some cases it was the only way to gather information about the patient experience.

Partnering with decision makers to maximize the possibility of work getting implemented

A fundamental principle of co-design is to include people *impacted* by the problem as well as those who have the power to *address* the problem (Bammer 2013). We were missing the latter. While the project itself was borne out of the interest of a local task group of decision makers tackling ALC challenges, this group disbanded during the early stages of the project. We eventually found other practice communities to share our work; however, more deliberate engagement with decision makers throughout the project would have helped us position our work for greater uptake.

Rediscovering purpose between projects

Although our project has ended, the ALC Patient and Caregiver Advisory Council still has bimonthly Zoom meetings. We are applying for additional funding and looking for hospital partners to implement and evaluate our intervention in practice. In the interim, we have invited those doing similar work to our council meetings. For example, we have learned about new care units at Trillium Health Partners and Health Sciences North that aim to prevent ALC-related discharge delays and keep people activated during care transitions. These may be sites for

TABLE 1.
Guidance for reporting involvement of patients and the public, version 2, short form

Section and topic	Item	Page numbers
Aim	Report the aim of PPI in the study	49–50
Methods	Provide a clear description of the methods used for PPI in the study	50–51
Study results and outcomes	Report the results of PPI in the study, including both positive and negative outcomes	50–52
Discussion and conclusions	Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	52–53
Reflections/critical perspectives	Comment critically on the study, reflecting on the things that went well and those that did not	52

PPI = patient and public involvement.

our implementation and evaluation work.

Part Three: Dissemination Activities and Outcomes

Funding from OSSU helped us share our co-design work with patients, caregivers and care providers across Ontario and build on our findings. We published our findings in an international peer reviewed journal, *Health Expectations* (Kuluski et al. 2020), and presented our work virtually at two international conferences: Academy Health (Boston, MA) and the International Conference on Patient- and Family-Centered Care (Nashville, TN). The Council also created a website (https://www.bettercarejourney.com/), which outlines our work and shares tools and structured guidance for different audiences. Audio-visual content about the ALC experiences of some council members is included. Stakeholders wanting to test these tools in practice can use the contact information on our website to reach our team.

So what was the overall impact of this work?

Patients and caregivers had a platform to articulate their lived experience and co-designed an intervention that aims to improve care and communication during a delayed discharge. The broader system impact of our work remains to be seen as we strengthen and develop partnerships and look for opportunities to implement and evaluate our intervention in practice. See Table 1 for guidance on reporting involvement of patients and the public. HQ

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