



Trillium
Health Partners

INSTITUTE FOR
BETTER HEALTH

An Alternate Level of Care Plan

Our team has been focusing on ALC issues for several years with patients and caregivers, point of care providers, quality improvement leads, managers and decision makers across Ontario. **A Patient and Caregiver ALC Advisory Council was established two years ago with the mandate of bringing the patient and caregiver voice to our research.** The seven member Advisory Group has been actively involved in conducting working groups and co-design sessions with patients who have ALC experience, caregivers and care providers, across Ontario, Canada to learn about their experiences and outline components of an intervention that aim to improve these experiences. Table 1 outlines the components of the intervention that we have co-designed to date.

The intervention aims to address two core challenges that were identified by patients, caregivers and care providers: **1) poor communication**, and **2) lack of services** (no physical activation or psycho-social support). These challenges are consistent with what other ALC patients and caregivers have identified in other health systems.¹ While the challenges are consistently stated, solutions are unclear. Our teams' recent scoping review on leading practices to address ALC identified no studies that partnered with patients, caregivers and care providers, with lived experience of ALC, to co-design an intervention (manuscript submitted). Co-design is important to ensure that an intervention captures what is valued by patients, caregivers and care providers and directly address the challenges felt in their lived experiences.

Table 1: Intervention

Intervention Component	
Communication	Within 24 hours of being designated ALC, patient and caregiver (if caregiver is available) are assigned a key point person from the unit (e.g., social worker)
	Communication guide (see Appendix) is used by point person and patient/caregiver to guide a conversation about what it means to be ALC, what to expect, and how to plan for next steps, patient and caregiver goals, capacity and concerns.
	At least once/week the point person follows up with patient and caregiver to provide update (estimated discharge date) and apprise information previously collected and answer questions.
Activation	
<i>Physical</i>	Each day the physiotherapist, physio assistant, occupational therapist, recreation therapist or nurse gets patient out of bed and dressed.
	A minimum of 10 minutes of mobilization is provided or wheelchair/seated exercises are completed over a 10-minute period for non-ambulating patients.
<i>Psychosocial</i>	Unit volunteer connects with patient and caregiver three times/week to offer available resources (patient activities in hospital, use of iPads, cross-word puzzles, books, etc.)

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The intervention addresses core gaps identified by patients, caregivers and providers at Trillium Health Partners and other hospitals across Ontario. Usual care for ALC patients varies but is typically characterized by little to no physical activation, uncertainty due to communication break-down and lack of a clear point person to manage next steps, elicit patient goals and manage expectations.¹⁻³ Our communication guide (Appendix) outlines the topics and suggested questions for providers, patients and caregivers to use during the ALC period. Patients and caregivers who previously had an ALC status, identified key pieces of information (and corresponding questions) that, in hindsight, would have been helpful in helping them prepare for their care transition. The intervention considers the resources available on medicine units at THP (the presence of volunteers three days/week and an interdisciplinary team).

The intervention components align with the eight aspects of patient centeredness as outlined by the Picker Institute: respect for patient preferences and needs; information and communication; coordination and integration of care; emotional support; physical comfort; involvement of caregivers (family); continuity of transition from hospital to home and access to care.⁴ Similarly, the four components of patient centered care as defined by the Institute for Patient and Family Centered Care is addressed in our intervention: dignity and respect (listening to and honoring patient and family wishes); information sharing (sharing information in a timely and honest way); participation (patients and families participating in decision-making in a way that works for them) and collaboration (patients and families participating in program development like co-design). A growing body of research is demonstrating a link between practices that incorporate these patient centered practices and better experiences, outcomes and costs.⁵

Evidence Supporting Intervention- Communication Component- Previous research has shown the benefits of improving communication between providers, patients and caregivers. In our previous study involving 172 patients with multi-morbidity and their caregivers from Canada and New Zealand⁶, clear communication with the care team (in particular, having access to a point person, feeling heard and understood during care interactions and having expectations managed) were considered the most valued components of a care experience.^{7,8} and were also very important to care providers. In an observational cohort study by Stewart et al⁹ good communication was characterized by patients reaching *common ground* with their care provider (i.e., being on the same page and developing trust). Achieving common ground was associated with better recovery, improved emotional health and fewer diagnostic tests. Similarly, in a systematic review by Doyle et al⁵ better communication and continuity of care between care providers and patients was associated with greater adherence to (and understanding of) medical treatments, increased preventative care (screening) and optimal resource use (hospital use, etc.). On the flip side, poor communication can lead to frustration and confusion for patients and caregivers and can generate a significant economic cost. Agarwal et al¹⁰ estimated that hospitals in the United States waste \$6 billion annually due to communication issues during patient discharge.

Activation Component: Physical and Psychosocial- In addition to costs, previous research has demonstrated the risk of functional decline among hospital patients, particularly among patients who are awaiting discharge.^{11,12} In a study based in two hospitals in New Brunswick by McCloskey et al, ALC patients' mean length of stay was 379.6 days and the majority of patients experienced functional decline during their prolonged hospitalization¹² due to extended periods of time spent in bed. In another Canadian study of General Internal Medicine patients in a large tertiary care hospital, ALC patients had significantly higher median length of stays, higher hospital costs and more nosocomial infections than non-ALC patients.¹³ In a systematic review conducted by Rojas-Garcia et al, ALC was associated with mortality, infections, functional decline and depression. The qualitative studies in this review captured staff stress due to pressures to free up beds and strained inter-professional relationships, which

negatively impacted patient care.¹⁴ To combat the issue of functional decline, the United Kingdom (and recently Alberta Health Services) implemented the End PJ Paralysis initiative. Getting patients up, out of bed and dressed not only helps to prevent physical deconditioning but facilitates a dignified care experience. After the PJ Paralysis initiative was implemented in the trauma and orthopedic unit at Nottingham University in the United Kingdom there was a 37% reduction in falls, 56% reduction in pressure ulcers and 80% reduction in patient complaints following this 70-day initiative.¹⁵

These examples demonstrate that the components of our intervention have been linked to positive patient outcomes in previous research. Most importantly, our co-designed intervention addresses issues of importance identified by patients, caregivers and providers, who were included as partners in the design process. It is important to understand how this work can be implemented in a Canadian context.

Therefore, the next stage of this research is to determine whether the intervention is feasible in practice a critical first step in implementation research as outlined by the Medical Research Council's guidelines on developing and evaluating complex interventions.¹⁶ The feasibility study will allow us to understand *how* to set up the intervention on clinical units, *how* the strategy works in practice, *which* processes need to be in place, the utility and meaningfulness of our chosen measures and *how* and *what* needs to be adapted/changed in preparation for future research (multi-site pilot studies and pragmatic trial). Feasibility studies are not designed to determine intervention effectiveness regarding a change in outcomes but rather, the *do-ability* of the intervention, before a larger, more resource intensive study, with an appropriate sample size and control group, is conducted.

References

1. Overall, A.C., S.J.T. Guilcher, L. Cadel, M. Asif, J. Li, and K. Kuluski, *Patient and caregiver experience with delayed discharge from a hospital setting: A scoping review*. Health Expect, 2019. **22**(5): p. 863-873.
2. Kuluski, K., J. Im, and M. McGeown, *"It's a waiting game" a qualitative study of the experience of carers of patients who require an alternate level of care*. BMC Health Serv Res, 2017. **17**(1): p. 318.
3. Cressman, G., J. Ploeg, H. Kirkpatrick, S. Kaasalainen, and C. McAiney, *Uncertainty and alternate level of care: a narrative study of the older patient and family caregiver experience*. Can J Nurs Res, 2013. **45**(4): p. 12-29.
4. Gerteis, M., S. Edgman-Levitan, J. Daley, and T. Delbanco, *Introduction: medicine and health from the patient's perspective*. 1993, Jossey-Bass San Francisco. p. 1-15.
5. Doyle, C., L. Lennox, and D. Bell, *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness*. BMJ Open, 2013. **3**(1).
6. Wodchis, W.P., T. Ashton, G.R. Baker, N. Sheridan, K. Kuluski, A. McKillop, et al., *A Research Program on Implementing Integrated Care for Older Adults with Complex Health Needs (iCOACH): An International Collaboration*. Int J Integr Care, 2018. **18**(2): p. 11.
7. Kuluski, K., A. Peckham, A. Gill, D. Gagnon, C. Wong-Cornall, A. McKillop, et al., *What is Important to Older People with Multimorbidity and Their Caregivers? Identifying Attributes of Person Centered Care from the User Perspective*. Int J Integr Care, 2019. **19**(3): p. 4.
8. Kuluski, K., A. Peckham, A. Gill, J. Arneja, F. Morton-Chang, J. Parsons, et al., *"You've got to look after yourself, to be able to look after them" a qualitative study of the unmet needs of caregivers of community based primary health care patients*. BMC Geriatr, 2018. **18**(1): p. 275.
9. Stewart, M., J.B. Brown, A. Donner, I.R. McWhinney, J. Oates, W.W. Weston, et al., *The impact of patient-centered care on outcomes*. J Fam Pract, 2000. **49**(9): p. 796-804.

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10. Agarwal, R., D.Z. Sands, and J.D. Schneider, *Quantifying the economic impact of communication inefficiencies in U.S. hospitals*. J Healthc Manag, 2010. **55**(4): p. 265-81; discussion 281-2.
11. Barnable, A., D. Welsh, E. Lundrigan, and C. Davis, *Analysis of the Influencing Factors Associated With Being Designated Alternate Level of Care*. Home Health Care Management & Practice, 2015. **27**(1): p. 3-12.
12. McCloskey, R., P. Jarrett, C. Stewart, and P. Nicholson, *Alternate level of care patients in hospitals: what does dementia have to do with this?* Can Geriatr J, 2014. **17**(3): p. 88-94.
13. Bai, A.D., C. Dai, S. Srivastava, C.A. Smith, and S.S. Gill, *Risk factors, costs and complications of delayed hospital discharge from internal medicine wards at a Canadian academic medical centre: retrospective cohort study*. BMC Health Serv Res, 2019. **19**(1): p. 935.
14. Rojas-Garcia, A., S. Turner, E. Pizzo, E. Hudson, J. Thomas, and R. Raine, *Impact and experiences of delayed discharge: A mixed-studies systematic review*. Health Expect, 2018. **21**(1): p. 41-56.
15. Health Service 360. *#EndPJPparalysis: Get up, get dressed, get moving*. nd [cited 2020 January 14]; Available from: <https://endpjpgparalysis.org/>.
16. Craig, P., P. Dieppe, S. Macintyre, S. Michie, I. Nazareth, and M. Petticrew. *Developing and evaluating complex interventions: Following considerable development in the field since 2006, MRC and NIHR have jointly commissioned an update of this guidance to be published in 2019*. nd [cited 2020 February 12]; Available from: <https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/>.