

CONFERENCE ABSTRACT

"She was just lying in bed for three days" The experiences of caregivers of patients who are stuck in hospital

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Introduction: Health systems in developed nations are striving to improve care experiences and quality. A common care quality issue is delayed hospital discharge, known in Canada as Alternate Level of Care (ALC). An ALC designation is given when a patient's treatment is complete but his/her next point of care (e.g. long-term care, assisted living, care at home) is unavailable. While ALC patients occupy hospital beds, care and activation usually decreases or even ceases, exacerbating their already heightened risk of functional decline, falls, and hospital-related adverse events. . ALC is also a systems issue: hospital beds are unavailable to incoming patients, causing emergency service backlogs, cancelled surgeries and delays. ALC also impacts patients and their family caregivers who fill these care gaps; however, little is known about personal care experiences, particularly among family caregivers.

Methods: Interviews were conducted with 30 caregivers across three health regions in Ontario, Canada with varying geographies, community resources and population characteristics. Interviews focused on caregivers' experiences of caring for loved ones who were designated ALC. Qualitative descriptive analysis was used to identify core themes.

Results: Core themes included: patient over person (patients no longer had medical needs but still required personal care); uncertain, confusing processes (steps in care were unclear); inconsistent quality of care delivery (between providers); caregivers addressing gaps in the system (caregivers provided support to patients while in hospital); and personalization of long-term care (caregivers wanted patients to be in a place that felt homelike, stimulating and in close proximity to them).

Discussion: Caregivers' roles continue while patients are hospitalized. ALC patients' physical and social needs are often neglected by the hospital, putting patients and caregivers at risk of additional decline. Caregivers strive to fill care gaps but factors related to geographic

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location, understanding of the health system and comfort in advocating shape their ability to do so.

Conclusion (w/ key findings): Caregivers play a critical, and often overlooked, role in meeting the care needs of patients during care transitions. An ALC designation creates additional uncertainty during an already vulnerable time. Ironically, patient and caregiver needs are ongoing but care within the hospital is considered 'complete'. The caregiver experience provides insight on health care system gaps, the importance of caregiver involvement within care teams and a need for tailored caregiver engagement strategies.

Lessons Learned: ALC is an issue that requires a collective response from health and social care systems (including acute and intermediate care hospitals, long-term care, homecare and primary care) with better engagement of caregivers, who oversee patient care within and beyond the hospital walls.

Limitations: This paper shares caregiver perspectives only. An analysis of the experiences of other stakeholders, including patients, providers, managers and decision-makers is required in order to act on the identified needs of caregivers.

Suggestions for Future Research: Future research by this team will engage patients and caregivers to co-design strategies to address delayed hospital discharge. The team will explore the experiences of providers and decision-makers and collect input on the implementation barriers and facilitators of such co-designed strategies.

Keywords: delayed hospital discharge; transitions of care; caregiver perspective; caregiver burnout; care journey
