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# BMJ Open Developing an in-depth understanding of patient and caregiver engagement across care transitions from hospital: protocol for a qualitative study exploring experiences in Canada

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## ABSTRACT

**Introduction** Patient and caregiver engagement is critical, and often compromised, at points of transition between care settings, which are more common, and more challenging, for patients with complex medical problems. The consequences of poor care transitions are well-documented, both for patients and caregivers, and for the healthcare system. With an ageing population, there is greater need to focus on care transition experiences of older adults, who are often more medically complex, and more likely to require care from multiple providers across settings. The overall goal of this study is to understand what factors facilitate or hinder patient and caregiver engagement through transitions in care, and how these current engagement practices align with a previously developed engagement framework (CHOICE Framework). This study also aims to co-develop resources needed to support engagement and identify how these resources and materials should be implemented in practice.

**Methods and analysis** This study uses ethnographic approaches to explore the dynamics of patient and caregiver engagement, or lack thereof, during care transitions across three regions within Ontario. With the help of a front-line champion, patients (n=18–24), caregivers (n=18–24) and healthcare providers (n=36–54) are recruited from an acute care hospital unit (or similar) and followed through their care journey. Data are collected using in-depth semi-structured interviews. Workshops will be held to co-develop strategies and a plan for future implementation of resources and materials. Analysis of the data will use inductive and deductive coding techniques.

**Ethics and dissemination** Ethics clearance was obtained through the Western University Research Ethics Board, University of Windsor Research Ethics Board and the University of Waterloo Office of Research Ethics. The findings from this study are intended to contribute valuable evidence to further bridge the knowledge to practice gap in patient and caregiver engagement through care transitions. Findings will be disseminated through publications, conference presentations and reports.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study will be conducted in three mid-sized cities, with acute and rehabilitative care programs for older adults.
- ⇒ We aim to interview patients, caregivers and health-care providers at each point in the care journey.
- ⇒ We are leveraging an existing patient and caregiver framework to enhance our understanding of engagement practices during transitions in care.
- ⇒ The study sites are located in one province, Ontario, and may not be representative of all health systems across Canada.

## INTRODUCTION

### Background and rationale

There is growing recognition of the importance and benefits of patient-centred and caregiver-centred approaches for older adults with complex medical needs, particularly when multiple providers are involved in determining goals and care plans.<sup>1</sup> Patient and caregiver engagement is a central element to operationalising person-centred and caregiver-centred care.<sup>1–3</sup> Broadly defined, patient engagement is patients having an active role in their own healthcare,<sup>4 5</sup> often with close involvement of their caregivers. This engagement is important for providers to understand patients' needs, preferences and contexts and to support coordination of health and community services.

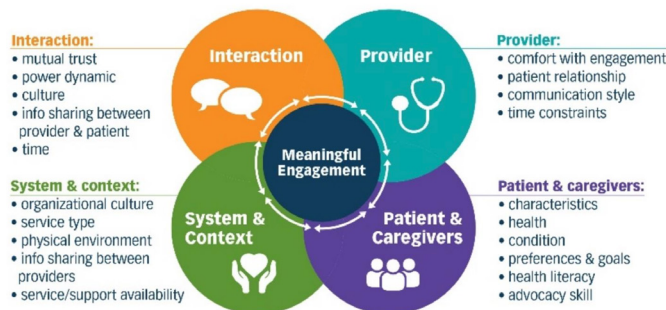
Despite the widely recognised benefits of greater patient/caregiver engagement in decision-making, there is a lack of consensus on how this can be achieved and supported within and across healthcare organisations and sectors.<sup>6 7</sup> In an engaged environment,

patients, caregivers, and clinicians jointly value and share each other's knowledge and expertise, as partners,<sup>8</sup> learning together about advantages and disadvantages associated with various treatment options from each perspective and arriving together at the most prudent decision.<sup>9–11</sup> Often however, older adults have been left out of decision-making.<sup>12</sup> Lack of engagement is even more significant for older adults who have complex conditions, hearing and sight challenges, or where English may not be the first language. Patient and caregiver engagement is often compromised at points of transition between care settings,<sup>13,14</sup> which are more common, and more challenging, for patients with complex medical problems, or who have experienced a catastrophic event such as a hip fracture or stroke. Healthcare system consequences include increased healthcare costs due to higher readmission rates,<sup>15</sup> longer lengths of stay<sup>16</sup> and increased emergency department use.<sup>17,18</sup> Prior research focusing on the care transition experiences of complex older patients—who often receive care in a variety of settings from multiple care providers—has found such transitions to be characterised by a lack of engagement of patients/caregivers in decision-making.<sup>14,19</sup>

Exploring older adult patients' and caregivers' experiences of care transitions has been identified as an area of opportunity to improve overall care management for older adult patients with complex needs.<sup>7,13,14</sup> This study is imperative to the field as it seeks to contribute novel understanding of the knowledge, strategies and resources necessary for improved engagement of older adult patients and caregivers during transitions of care (ie, from preparing for discharge through to admission in another facility or returning to the community). In addition, this study will also offer an understanding of how these resources could be implemented into practice. Although many interventions have been implemented to reduce the adverse outcomes often associated with care transitions, engagement of patients and their caregivers to support improved experiences and outcomes remains an area where additional work is critically needed.<sup>20</sup> Many gaps in knowledge remain, including: lack of consensus on how to best support caregiver engagement through care transitions, how to best embed patient engagement within all disciplines and across all services and how to overcome identified barriers to engagement, such as rushed healthcare interactions, language barriers, etc.<sup>7</sup>

### Theoretical framework

The theoretical framework guiding this work was previously developed by Stolee *et al* and Elliott *et al*, who conducted a realist synthesis on patient and caregiver engagement in healthcare decision-making—the Choosing Healthcare Options by Involving Canada's Elderly (CHOICE) project.<sup>21,22</sup> The framework (see figure 1) is comprised of four main domains to support meaningful engagement: the patient and caregivers, healthcare provider (HCP), interaction/relationship and consideration of the broader healthcare system. Central



**Figure 1** Four domains to support patient and caregiver engagement in clinical decision-making.

to the framework is the development of a relationship with the patient and caregiver that is sensitive to the needs and circumstances of the patient, caregiver, HCPs and care context. The framework theorises how the skills and knowledge of the patient, their caregivers and the HCPs may influence the desired level of engagement. Communication among patients, caregivers and HCPs is identified as key to the development of an open, honest and trusting relationship. The CHOICE framework identifies broad principles of engagement; however, there is still a gap in understanding how the framework can be translated into practice, especially during care transitions. For the purposes of this project, the data collection tools and analysis process will be guided by the framework domains.

### Aims and objectives

The design of this research protocol aims to answer the following questions: *What factors facilitate or hinder patient and caregiver engagement during care transitions, and how do current engagement practices align with the CHOICE framework?* Our objectives are to:

1. Understand current engagement practices during care transitions, including barriers and facilitators to engagement.
2. Understand how current practices of engagement align with the CHOICE framework.
3. Determine, in partnership with patients, caregivers and providers, what resources and materials are needed to support engagement in care transitions.
4. Relatedly, understand how these resources and materials could be implemented into practice.

## METHODS AND ANALYSIS

### Study design

Our study follows two phases: phase I implements a focused ethnography<sup>23–25</sup> to explore the dynamic interactions at play within the care transitions context—specifically patient and caregiver engagement (or lack thereof) in healthcare settings in three regions of the Canadian province of Ontario. A focused-ethnographic approach allows us to hone in on our specific group of interest and health problem—for example, patients with complex medical needs<sup>23,24</sup> while using ethnographic methods to understand their experiences of receiving health

services<sup>26</sup> within this context; such methods will include in-depth interviews and observations (where possible, noting many of the interactions may be virtual due to COVID-19 restrictions), among a range of patients, caregivers and HCPs.

In phase II, we use a codesign approach<sup>27 28</sup> by bringing together patients, caregivers and HCPs to participate in codesign workshops. The aim of the workshops is to develop transition strategies and resources, as well as a plan for implementation.

This work will be completed between Summer 2022 and Spring 2025.

### Study setting and context

Our study takes place in three sites in Ontario, Canada, all medium-sized urban centres. Our aim is to characterise the care transition experience (rather than attempt to compare and contrast across different-sized centres), allowing us to understand if/how current practices in these sites align with the CHOICE framework. Conversations with staff and leadership at each site, prior to receiving funding for the project, confirmed their recognition of care transitions as a priority concern, as well as their interest to participate in this research. The sites are described below:

1. Site 1: the main hospital campus has an 11-bed acute care of the elderly (ACE) unit focused on caring for older adults with a goal of discharge within 5 days. Patients who require longer stays are admitted to a different hospital campus which houses a neurobehavioural unit, a geriatric assessment unit and an inpatient rehabilitation unit, for a combined total of 46 beds.
2. Site 2: a 14-bed acute medicine unit is located in an urban teaching hospital. Patients stay on average 10 days before being discharged. For patients needing in-patient rehabilitation care, they are transferred to a different hospital, which includes a 30-bed geriatric rehabilitation unit.
3. Site 3: the hospital has acute care units and a 30-bed geriatric rehabilitation unit targeting patients with older adults needing specialised rehabilitation care.

In each region, discharge locations from the above settings may include: rehabilitation hospitals, residential long-term care homes and home with or without home and community care services.

This project will take place over a 3-year time period. Phase I is underway and will continue until all participants have been recruited. Phase II will start immediately following phase I data collection and preliminary analysis. This work is taking place within the context of the COVID-19 pandemic response and recovery environment, and we outline the implications of this at the end of the paper.

### Study sampling and recruitment

Prior to recruitment, researchers will meet with department leadership at each hospital (acute care facility

and rehab facility) to discuss recruitment processes and build partnerships. Leadership is responsible for identifying site champions who can assist researchers with the recruitment process. To begin, HCPs in each organisation will be informed of the study by the site champion. An information letter outlining the purpose of the study, expectations, benefits and risks will be reviewed with potential HCP participants prior to obtaining consent. We will aim to recruit a sample of allied health, nursing and physicians from the various healthcare organisations (eg, hospital and community) who are able to provide specific information about the transition process. We will also work with community agencies and primary care organisations to identify HCPs who can speak to care processes as patients transition from hospital back to the community.

Next, patients and their caregivers will be recruited during inpatient stays on the acute or similar units. A consent to contact process will be used, whereby the unit champion (eg, a nurse lead or physician) obtains permission from potential interested participants and passes the information on to the researchers for follow-up and consent. On obtaining verbal consent to participate in the study, the local researcher will also ask if the patient has a caregiver who they could contact. If yes, the researcher will obtain permission to contact the caregiver to explain the study and obtain consent. We have used this method of recruitment successfully in prior research.<sup>14 19</sup>

Inclusion and exclusion criteria for this study are as follows: for patients, there will be intentional recruitment of individuals with a range of perspectives including diversity based on gender identity and ethnocultural backgrounds, patients who are 70+ years of age with complex health conditions and who are English speaking. Halfway through recruitment, we will review participant information to ensure we have adequate representation of diverse backgrounds, and adjust recruitment strategies if needed. We are not excluding based on cognitive impairment, and clinical gatekeepers will make the judgement on capacity to provide consent. If the patient cannot provide consent, gatekeepers could approach the caregiver to see if they are interested in participating. Individuals will be ineligible if they are coming to the hospital from long-term care. For caregivers, these individuals will be recruited based on identification by the patient (or for those with cognitive impairment, identified by gatekeeper) and English speaking. For HCPs, we will recruit those who typically participate in the discharge planning and transition process and are involved in patient care at points of discharge/transitions and English speaking.

### Recruitment for phase II (codesign)

Participants from phase I are informed about the phase II codesign sessions and invited to participate. The codesign sessions are to further discuss findings and develop resources. As such, they will take place after all the interviews have concluded. If a participant indicates that they

**Table 1** Sample interview questions for patients, caregivers and healthcare providers

Patients	Caregivers	Healthcare providers
<ul style="list-style-type: none"> <li>▶ Can you walk me through what happened when you were admitted to (<i>insert location</i>)?</li> <li>▶ Did you receive any information about your care and what to expect?</li> <li>▶ In general, how did you feel about your involvement with your day-to-day care while you were at (<i>insert location</i>)?</li> <li>▶ In the days leading up to discharge, when you had a question about your care, how did you go about finding an answer?</li> </ul>	<ul style="list-style-type: none"> <li>▶ Were your needs or preferences as a caregiver asked about or discussed by (<i>name of patient</i>)'s healthcare provider(s)?</li> <li>▶ Did the care team treat you as a source of knowledge? If yes, how?</li> <li>▶ How were you involved in decisions about discharge planning and future care arrangements? Tell me more about that.... Do you feel you were involved about as much as you wanted to be?</li> </ul>	<ul style="list-style-type: none"> <li>▶ To what extent are patients and caregivers involved in decision making about their own care?</li> <li>▶ What are things that make it easier to involve patients/caregivers in care planning? What are things that make the process of engagement difficult?</li> <li>▶ Thinking about a patient being discharged to (<i>insert example discharge location</i>); can you walk me through how you prepare the patient/caregiver for the transition?</li> </ul>

are interested, the local researcher will follow up with them at a later date.

### Study data collection

Data collection will occur in two phases: (1) qualitative semistructured interviews and field notes and (2) codesign workshops. We anticipate that phase I data collection will continue to take place through 2023 and early 2024, and codesign workshops will be held in summer 2024. Data collection procedures are outlined in further detail below.

#### Phase I: qualitative interviews and field notes

Sociodemographic data will be collected about all participants during the first interview. We will conduct in-depth semistructured interviews with patients, their caregivers and HCPs to gain an in-depth understanding of experiences and processes related to patient and caregiver engagement and factors that support or hinder engagement at various transition points. With the participant's permission, interviews (anticipated to range from 30 to 60 min) will be audio/video recorded and transcribed verbatim. A list of sample interview questions is included below in [table 1](#), and full interview guides are included as online supplemental material. Field notes will be written when interviews are completed. The field journal will use a structured format based on recommendations for ethnographic research.<sup>29 30</sup>

We have pilot-tested the interview guides to be used with patients, caregivers and HCPs and found these to be feasible and acceptable. We aim to recruit 6–8 patients (and their caregivers) per study region, for a total of 18–24 patients and 18–24 caregivers. Interviews with patients and caregivers will be conducted at each transition point (eg, ACE unit to inpatient rehabilitation to home or ACE unit to outpatient rehabilitation to home care). We aim to interview a sample of HCPs who are involved in the discharge process at each location, including the community (eg, home care and primary care). We anticipate approximately 12–18 provider interviews per region, for a total of 36–54. Based on previous work<sup>14</sup> with similar aims

and approach, we believe our HCP and patient/caregiver sample sizes are sufficient for data adequacy, as described by Vasileiou *et al.*<sup>31</sup>

#### Phase II: codesign sessions

Following the analysis of data collected in phase I, the research team will hold codesign sessions,<sup>27</sup> hereafter referred to as workshops, with patients, caregivers and HCPs to develop strategies and a plan for implementation of resources and materials. Information collected in phase I will be the basis for the discussions in the workshops. From phase I, we will identify current practices of engagement, barriers and facilitators. The participants in the workshops (phase II) will review findings from phase I, discuss ideas to improve engagement within the context of the CHOICE framework, as well as brainstorm how new ideas/resources/solutions should be implemented into practice (see [table 2](#) for sample workshop questions, these will be modified following results from phase I). We will actively recruit participants for the workshop representing various backgrounds (eg, roles, length of time practising), experiences (eg, different care trajectories) and differences in gender identity. During each workshop, notes and observations will be collected. This phase will consist of workshops in each region and are further described below:

1. Workshop 1: in each region, a half-day workshop will be held with patient and caregiver participants to review findings. Using data from phase I, a facilitator will take participants through a series of interactive activities to further understand 'why' engagement did or did not happen under certain situations. Participants will also discuss what supported engagement or what resources/materials are needed to improve engagement.
2. Workshop 2: in each region, a half-day workshop will be held with HCP participants to review findings. Similar to workshop 1, a facilitator will work with participants to discuss challenges and strategies to overcome barriers. Participants will also discuss what resources/materials are needed to support engagement and how

**Table 2** Sample workshop questions for patients, caregivers and healthcare providers

Patient and caregiver workshop	Healthcare provider workshop
<ul style="list-style-type: none"> <li>▶ We would like to create resources and materials for patients and caregivers on engagement strategies. What do you think would be helpful for you to know?               <ul style="list-style-type: none"> <li>– <b>Examples:</b> A guide of questions to ask providers during discharge planning; a resource guide for patients/families on what to expect during transition process</li> </ul> </li> <li>▶ We are creating resources and materials to assist healthcare providers in the process of engaging patients/caregiver in care planning. What resources/things would you find helpful?               <ul style="list-style-type: none"> <li>– <b>Probe:</b> Are there specific questions that healthcare providers should ask to better understand you/your situation?</li> </ul> </li> <li>▶ How should providers make you feel more comfortable to participate in care planning discussions? What would make you more comfortable?</li> </ul>	<ul style="list-style-type: none"> <li>▶ We are creating resources and materials to assist healthcare providers in the process of engaging patients/caregiver in care planning/transition planning. What resources/materials would you find helpful?</li> <li>▶ What kind of educational session or workshop would be helpful for you to learn about strategies for engaging patients/caregivers in the planning process?               <ul style="list-style-type: none"> <li>– <b>Probe:</b> sample questions to ask patients and caregivers when developing care plans</li> </ul> </li> <li>▶ There were some ... barriers to engagement identified in phase one interviews, how can we overcome these barriers?...facilitators to engagement identified in phase one interviews, how can we build on these facilitators?               <ul style="list-style-type: none"> <li>– <b>Probe:</b> Link with CHOICE domains</li> </ul> </li> </ul>

CHOICE, Choosing Healthcare Options by Involving Canada's Elderly.

the resources/materials should be implemented into practice during care transitions.

3. Workshop 3: participants (patients, caregivers and HCPs) will participate in a workshop together to *codevelop* materials based on discussions from the previous workshops held with each participant group. Participants will also discuss *how* the resources/materials should be implemented into practice during care transitions. We have had experience facilitating similar sessions and understand the importance of giving equal voice to all parties participating.

Additionally, patient and caregiver participants will be reimbursed for their time. Every effort will be made to host these sessions in-person; however, if they need to be virtual, support will be provided to ensure patients and caregivers are able to participate and contribute fully to the discussions and activities online.

### Data analysis

#### Phase I: qualitative interviews and observation/field notes

The research team will meet once a month during the data gathering process. Team members will describe progress and challenges, will ensure that methods are being consistently applied across the cases and will share perspectives emerging from the memoing process. Formal coding and theming will begin only when the research team agrees that data adequacy has been reached and data gathering ends.<sup>31</sup>

Line-by-line coding using methods by Lofland<sup>32</sup> will be conducted. Researchers will read through the dataset and will create codes using NVivo V.12. When coding is complete, we will then identify themes using a clustering technique.<sup>33 34</sup> Each cluster will have a proposed name, brief description, illustrative quotations from the data and a list of codes that support the theme. We will also conduct additional analyses of our data, using directed coding<sup>34</sup> by mapping our findings to the CHOICE

Engagement Framework.<sup>22</sup> This will further help us understand barriers and facilitators of implementing the CHOICE framework.

Given the gendered nature of caregiving,<sup>35</sup> and sex-based differences in care recovery,<sup>36 37</sup> we will create codes for sex and gender in our analysis. In qualitative analysis software, we will explicitly code for sex and gender, and their relationship(s) to other codes and themes. Of note, sex and gender-based analysis is an expectation of our granting agency, and a planned part of our analysis. We do not anticipate a sufficiently diverse sample to allow for analysis based on ethnicity, but will be alert to any related themes that may emerge from the data.

#### Phase II: codesign sessions

Notes taken and documents produced during the workshops will be transcribed and reviewed. The data will be analysed using directed coding guided by Chaudoir's multilevel framework, which builds on the Consolidated Framework for Implementation Research,<sup>38 39</sup> with the addition of central elements for the patient, caregiver and provider, and with which we have experience.<sup>40</sup> Using this framework to guide the analysis will help the research team understand how resources/materials should be implemented into practice. Following phase II analysis, we anticipate the creation of a guide to support implementation of tools, resources and strategies to enhance engagement in care transitions, aligned with the CHOICE framework.

#### Patient and public involvement

Our proposed research project is in support of the engagement of older adults in healthcare decision-making. We have valued the input of older adults and their caregivers in all aspects of our own work. To provide a sustainable structure for our own engagement with older adults, in 2013 we launched the Seniors Helping As Research



Partners (SHARP) group, which includes more than 60 older adults from the community ([www.uwaterloo.ca/ghs/SHARP](http://www.uwaterloo.ca/ghs/SHARP)). This group is made up of individuals with diverse backgrounds, experiences and health statuses. We have built a collaborative partnership with this group and are implementing evidence-based principles for engaging older adults and their caregivers in healthcare research.<sup>21 41</sup> Our work with this group has confirmed for us that older adults want to be engaged in meaningful relationships with researchers. With this goal in mind, we will continue to work with the SHARP group as integral partners in the current research project. Patient and caregiver partners interested in this work will assist with review of the interview guides, analysis of the data and cofacilitating the workshops where possible. Patient and caregiver partners will also participate in regular team meetings to provide feedback and input throughout the project.

## ETHICS AND DISSEMINATION

Through the codesign phase (phase II), researchers, in partnership with patients, caregivers and HCPs, will codevelop resources and processes to enhance engagement in care transitions and a related implementation guide. These resources will highlight the lessons learnt from the study sites, as well as suggestions for improvements, in alignment with the CHOICE framework. The resource will be disseminated through provincial and national networks aimed at improving care experiences and outcomes for older adults. Additionally, findings from the study will be disseminated through publications, conference presentations and lay summary reports.

Ethics approval was obtained through the Western University Research Ethics Board, the University of Windsor Research Ethics Board and the University of Waterloo Office of Research Ethics.

## COVID-19 interruptions and delays

This proposal was submitted for research funding in February 2020, 1 month before the COVID-19 pandemic was declared. At that time, we had proposed that research staff members would be recruiting people and conducting interviews in-person. We also proposed that an observational component of data collection would be carried out. We received notification of funding during a time that our hospital and healthcare partners were unable to participate in research activities, thus, delaying our project. Since receiving ethical clearance, we have continued to incorporate a fluid process that affords us the flexibility to adjust to the timelines created by the pandemic. Operationally, this has created pauses with initiating our relationship building with staff, and recruitment of patients and caregivers. Additionally, due to the frequent redeployment of hospital staff, our gatekeepers and champions were sometimes replaced, further delaying the start of this project. We have modified the original data collection protocol to align with hospital

and university COVID-19 protocols (eg, where possible, collect data virtually). We will continue to make changes to our protocol as the healthcare environment changes.

While the changes and challenges that have come from delivering healthcare during the pandemic have made conducting this research more complex, it has also made this work more critical than ever. Unit lockdowns, visitor and caregiver restrictions, isolation protocols and staff shortages have become commonplace in hospitals across Canada, and all have the potential to impede patient and caregiver engagement procedures and strategies during care transitions. A recent scoping review of patient engagement during COVID-19 conducted by Cadell *et al*<sup>42</sup> emphasises the need for more research into understanding the strategies and processes that allow for patient engagement to continue during times of major disruption. Our work will allow us to explore if, and how, engagement approaches during care transitions have evolved over the course of the pandemic. The research will provide a richer understanding of current engagement practices, and how we can improve these practices for the current context and during future disruptions. This work aims to understand current care experiences of under-represented voices involving medically complex older adults, a vulnerable population within Canada, at critical transition points in care.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods and analysis section for further details.

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