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Understanding Patient and Family Perspectives of Accelerated Discharge Planning in the Critically Ill

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Understanding Patient and Family Perspectives of Accelerated Discharge Planning in

the Critically Ill

by

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ABSTRACT

Accelerated discharge, which involves *initiation of discharge planning earlier in patients' intensive care unit (ICU) stay*, has become more common to reduce discharge delays and mitigate capacity strain challenges experienced in Canadian ICUs. Successful accelerated discharge planning relies on effective clinician communication and partnering with patients and family caregivers, who are the only constant throughout the care journey. To best enable family caregivers to feel self-efficacious in collaborating in the care of their critically ill loved one, their perspectives on the practice of accelerated discharge planning are needed to help facilitate successful transitions in care. The work presented in this thesis sought to understand patient and family perspectives on accelerated discharge planning as with their insights on supportive elements in accelerated discharge plans. We conducted 45-minute virtual semi-structured interviews with former critically ill patients and family caregivers of former critically ill patients between October 2021 and January 2022. We used inductive, reflexive thematic analysis to identify relevant themes and subthemes. Key themes identified following thematic analysis from seven participants (n=2 former critically ill patients, n=5 family caregivers) included: discharge planning process and stakeholder goal alignment (i.e., benefits of earlier planning, communication and continuity of care, and desire for stakeholder collaboration in care), patient and family support needs in accelerated discharge planning (i.e., informational support, psychological support, and logistical support), scope of support across care settings (i.e., form and timing of supports), individuality of dyads (i.e., condition, capacity, and environmental characteristics specific to each dyad), facilitators and barriers to accelerated discharge

planning at the individual and structural level. The work presented in this thesis suggest that patients and families are receptive to accelerated discharge planning because accelerated discharge planning may provide opportunities for patients and family that are not present in current models of discharge; that is, there is alignment of objectives between this transition in care model and patient and family goals of care. Individualized, realistic accelerated discharge plans that provide informational, psychological, and logistical supports may help facilitate successful transitions in care.

PREFACE

The manuscript cited below will be submitted to Canadian Journal of Anesthesia for publication and presented in its entirety as a chapter in this thesis. Senior authors were involved in study conceptualization and design. The first author conducted the analysis, interpreted the results, and wrote the manuscript. All authors critically revised the manuscript and made substantial intellectual contributions.

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DEDICATION

To my partner, Luc.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

LIST OF ABBREVIATIONS

ACTIVATE: Activating family Caregivers in The Identification, preVention and mAnagemenT of dElirium

AD: Accelerated discharge

APACHE-II: Acute Physiology and Chronic Health Evaluation II

CHREB: Conjoint Health Research Ethics Board

CIHR: Canadian Institute of Health Research

COREQ: Consolidated Criteria for Reporting of Qualitative Research

F: Family caregiver of former critically ill patient

ICU: Intensive care unit

IQR: Interquartile range

P: Former critically ill patient

PICS: Post-intensive care syndrome

PODS: Patient-oriented discharge summary

QUAL→ quan: Sequential exploratory mixed methods

SCNs: Services' Strategic Clinical Networks

CHAPTER 1: INTRODUCTION

1.1 Overview of Research Project

Critically ill patients admitted to intensive care units (ICU) are among the sickest in our healthcare system and their discharge is one of the highest risk transitions in care.(1) Historically, ICU discharge followed a linear care model, where upon stabilization of acute illness, planning for discharge was initiated and patients transitioned to progressively lower-intensity care teams and locations (e.g., wards, step-down units) before discharge back into the community.(2,3) However, this model may not be feasible in the long-term due to the increasing volume of ICU admissions and decreasing ward bed availability.(4) Thus, to ensure efficient use of hospital resources, reduce length of hospital stay, transfer to ward delays, redundancy, and the number of transitions in care, both direct discharge home and accelerated discharge to the ward have become more common in the Canadian healthcare system; in a 10-year cohort study by Martin and colleagues, they found that among 174 ICUs in Ontario the annual rate of individuals bypassing the linear model of discharge from ICU increased from 18.6% in 2007 to 23.1% in 2017 (incidence rate ratio, 1.02 per year; 95% CI, 1.02–1.03; $p < 0.0001$).(3–6) While the potential benefits of direct discharge home (from hospital) intuitively make sense (reduced length of hospital stay, redundancy, and transitions in care), accelerated discharge to ward requires further justification. Upon stabilization of acute illness, many ICU patients meet discharge criteria and are ready to be transferred to lower intensity wards, but transfer to ward is not possible due to various reasons in the downstream units.(7) This results in transfer to ward delays and consequent increased cost, hospital length of stay, and patient flow failure.(8) Accelerated discharge to ward seeks to minimize these sub-optimal processes by initiating the planning for

2

discharge upon ICU admission, rather than upon stabilization of illness, so that transitions in care can occur as soon as the patient meets discharge criteria. Thus, both methods, discharge directly home and accelerated discharge to ward, require accelerated discharge planning, which is planning for discharge upon ICU admission.

Successful accelerated discharge planning relies on two critical pillars: i) effective communication and coordination between clinicians; and ii) partnering with patients and family caregivers. Effective communication and coordination between clinicians has been the primary focus in studies to date, so research must broaden the focus to partnering with patients and families and be inclusive of other relevant stakeholders' perspectives.(2,8) Patients and family caregivers are the only constant during transitions in care and families key advocates for the patient.(9) It is paramount to ensure supports are in place to prepare critically ill patients and their families to become active partners during transitions in care. However, studies have identified a dissonance between traditional researcher-identified priorities compared to patient priorities.(10) Differences in priorities may stem from the distinct process- versus experience-informed perspectives of clinicians and researchers compared to patients and family caregivers, respectively.(8) This dissonance underscores the importance of ascertaining patient and family caregiver perspectives directly and through open discussion in order to gain accurate insights on this stakeholder group's perspective and priorities.

Understanding patient and family caregiver perspectives of accelerated discharge planning in the critically ill will provide a foundation to develop accelerated discharge planning protocols that consider the perspectives of a broader group of stakeholders (clinicians, healthcare systems, and patients and family caregivers). To

best enable family caregivers to feel confident and prepared for monitoring and attending to the needs of their critically ill family member, their insights on key elements in accelerated discharge plans are essential for successful transitions in care. To our knowledge, there are currently no studies evaluating patient and family caregiver perspectives of accelerated discharge planning from ICU. Thus, the objectives of this thesis are to understand the perspectives of former critically ill patients and family caregivers of former critically ill patients (herein referred to patient and family, respectively) on accelerated discharge planning.

1.2 Literature Review

1.2.1 Intensive Care Units

ICUs are resource intensive units that leverage both advanced life-sustaining monitoring technologies and high staff-to-patient ratio with expertise from multi-disciplinary care teams, including but not limited to: critical care physicians, nurses, pharmacists, respiratory therapists, physical therapists, occupational therapists, dieticians, and clinical psychologists.(11) Annually in Canada (excluding Quebec), ICUs provide care to almost 250,000 of the sickest and most vulnerable individuals in the healthcare system, equating to approximately 9% of all hospital inpatient admissions.(11,12) The majority (80%) of ICU patients consist of urgent, emergency hospital admissions while the remainder are a result of planned admissions, typically following surgical procedure. (11) Mortality in ICU is three-times higher than that of general hospital settings (9% versus 3%, respectively), given the severity of illness and complexity of care. (11)

In a 2016 report on critical care usage in Canada, the Canadian Institute for Health Information (CIHI) found that most ICU beds are located in urban centers at large or teaching hospitals where occupancy rates are, on average, the highest at about 90%.(11) These urban facilities tended to encounter capacity challenges with periods of overcapacity equivalent to approximately 45 to 51 days in 2013-2014.(11) Thus, Canadian ICUs have historically encountered challenges with ICU capacity strain. In a qualitative study examining healthcare provider perceptions of consequences of ICU capacity strain, Bagshaw and colleagues found that there was "strong acknowledgement across disciplines that capacity strain potentially "jeopardizes the quality and safety of patient care" [in ICU]".(13) Supporting this notion, Weissman and colleagues found that ICU capacity strain is associated with decreased odds of receiving venous thromboembolism prophylaxis, which is strongly recommended for most critically ill patients to reduce morbidity and mortality and is used as a quality of care indicator (14), thus suggesting suboptimal quality of care.(15) In addition to suboptimal quality of care, ICU capacity strain may contribute to increased risk of adverse events (16) and mortality.(17) Thus, the implications of ICU capacity strain are disconcerting.

More than 50% of ICU patients are seniors aged 65 years and older.(1,11) Canada's population is aging and the already record proportion of seniors is steadily increasing (n=5.4 million, 15.3% of population as of July 1, 2013).(18,19) With Canada's aging population and advancing life-sustaining care, ICU admissions have increased by 12% between 2007 and 2014, and are projected, via modelling-based estimates, to continue to increase past 2026.(11,20) According to CIHI, this increase in ICU usage is

greater than that of acute hospitalizations overall (12% increase versus 7% increase, respectively).(11) The disproportional increase in critical care usage is economically troubling considering the average cost in 2013-2014 of a patient-day in ICU is approximately three times higher than that of one patient-day in other hospital wards ($3,592 CAD versus $1,135 CAD).(11) This poses a challenge to the finite ICU capacity and our healthcare system, as management of these patients is complex, time-consuming, and expensive due to the need for advanced technological care and constant monitoring.(21) Thus, in order to cope with the already capacity-strained ICUs and rapidly increasing ICU admissions and associated cost, sustainable long-term solutions that prioritize streamlined ICU care with subsequent, optimized discharge are essential.

1.2.2 Transitions in Care and Accelerated Discharge

Transitions in care encompass the handoff of responsibility and accountability of a patient to another team of healthcare providers as the patient transitons to another healthcare setting.(22) Research has demonstrated that upon tranitions in care, patients are at increased risk of adverse events (23,24) which may stem from breakdowns in communication between healthcare providers associated with lapses in medical care.(25–27) Health Services' Strategic Clinical Networks (SCNs) are provincial teams of patients, family, clinicians, researchers, and knowledge users tasked with developing strategies to improve the delivery of evidence-informed care.(28) Transitions in care were identified by our group, through partnership the Critical Care SCN, as a significant improvement opportunity and essential priority for critical care research in Alberta.(29,30) Due to the limited physiological reserve of ICU patients, their transitions

in care from the highly technological ICU to less acute environments (e.g., hospital ward, rehabilitation facility, or community) are among the most challenging, high-risk, and inefficient.(8) Upon transitions in care from ICU, patients are susceptible to increased risk of medical errors, adverse events (31,32), readmission (33), death (24), and suboptimal care.(8)

Historically, initiation of planning for ICU patient transfer to progressively lower-intensity care teams and locations (e.g. wards), before discharge back home into the community, would occur upon patient stabilization. However, immediate transfers to lower intensity wards are often not possible due to downstream ward logistics.(2) Stelfox and colleagues (9) observed a median duration of 25 hours (IQR 6-52 hours) from when transfer of care was requested to when the patient left the ICU and found that delay duration varied by hospital (median range 5–86 hours). Thus, initiation of discharge planning after patient stabilization may result in transfer to ward delays and subsequent increased cost, hospital length of stay, and patient flow failure.(8) In a qualitative study conducted in 14 hospitals in the United Kingdom, United States and Australia, former ICU patients cited significant challenges they encountered in their post-ICU rehabilitation as a result of fragmented and disjointed care across their recovery pathway.(34) Thus, this traditional linear care model is already being challenged due to patient-flow disruptions (9) and likely will not be feasible in the long-term due to increasing ICU admissions volume and decreasing ward bed availability.(2,4,8) Technological improvements in patient monitoring, care delivery, and communication have enabled novel transition in care models for certain lower-risk ICU patients.(6) In fact, approximately one quarter (23%) of adult ICU survivors in Ontario in

2017 have bypassed this linear care model and have been discharged directly into the community.(6) ICU survivors who are potential candidates to be directly discharged home from ICU tend to be of younger age, predicted to have a low chance of mortality on admission as determined by the Acute Physiologic Assessment and Chronic Health Evaluation II (APACHE-II) score, admitted to ICU with a diagnosis associated with a lower mortality rate (including but not limited to overdose, withdrawal, seizures, or metabolic coma), and have a less complicated ICU stay as indicated by $\leq$48 hours of mechanical ventilation.(4,6,35)

While the risks and benefits of this accelerated model of care in adults are beginning to be thoroughly examined, several notable benefits have been documented; these include fewer care transitions, shorter hospital lengths of stay (median decrease of 5.9 days), less redundant care, recovery in familiar and more comfortable environments, and no significant difference in adverse events.(3,4) Further, the accelerated discharge of preterm infants from neonatal intensive care units (NICU) has been well documented and endorsed by guidelines from American Academy of Pediatrics.(36–38) Two randomized controlled trials of accelerated direct discharge for low-birth-weight neonates from NICU suggest increased parent/caregiver satisfaction, decreased hospital length of stay, reduced healthcare utilization, and no difference in adverse events.(36,39) However, there are variable degrees of stakeholder comfort with the practice due to the sparse literature in adult ICU populations.(3,4,6,40) Thus, it is essential to examine and test the efficacy of accelerated discharge planning in adult ICUs, as well as integrate patient- and family-identified, support-centered elements in

accelerated discharge planning protocols to ensure that the quality of care is maintained

and all stakeholders feel *comfortable* with and *prepared* for this method of practice.

1.2.3 Accelerated Discharge Planning

In order to facilitate an accelerated model of discharge, accelerated discharge

planning must occur to efficiently coordinate care throughout the healthcare continuum.

Accelerated discharge planning, which is initiating the planning for discharge upon ICU

admission (as opposed to initiating the planning for discharge upon stabilization of the

patient), seeks to facilitate safer, more efficient, and better coordinated transitions in

care while reducing overall length of stay and subsequently lower the cost of care.(41)

Accelerated discharge planning encompasses both modalities of accelerated discharge

including i) direct discharge home and ii) accelerated linear discharge to ward from ICU,

as the planning required for both is similar.

Successful accelerated discharge planning relies on two fundamental pillars: 1.

effective communication and coordination between clinicians to reduce redundancy and;

2. partnering with patients and family to provide an element of consistency throughout

transitions in care.(9) Efforts to improve transitions in care have primarily focused on

clinician communication and coordination.(2,8) While improving effective communication

and coordination is necessary, it is insufficient in improving accelerated transitions in

care. Thus, it is essential to be inclusive of other relevant perspectives and shift the

focus to partnering with patients and families in accelerated discharge using both

modalities (directly into the community and accelerated to ward) from ICU.

Family (i.e., family or friends who provide physical, mental, or emotional support

to the patient) are vital partners to patient care within and beyond the ICU, with 75% of

ICU patients requiring family assistance up to two months post discharge.(42) Families are essential stakeholders both during and after transitions in care. Thus, it is paramount to ensure supports are in place to empower family of critically ill patients to be active partners during and after transitions. These supports, identified by our group, could include but are not limited to: the development of patient-oriented discharge summaries to inform and equip patients discharged from ICU and their family about the patient's health and care needs through a series of information elements essential for provision of discharge-specific information; family participation in multidisciplinary ICU care rounds to build caregiver efficacy in their oversight of continuity of care once transitioned out of ICU; and leveraging use of peer support groups to improve transitions in care.(43)

1.2.4 Patient-Oriented Research

To effectively generate knowledge to inform accelerated discharge planning protocols, all stakeholder views must be identified and considered. Key stakeholders in accelerated discharge planning include: patients, families, physicians, nurses, and healthcare service providers.

The Canadian Institutes of Health Research (CIHR) defines patient-oriented research as "*a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes (pg. 5)*."(44) As researchers, it is not prudent to attempt to anticipate the priorities of patients as the incongruence in traditional researcher-identified priorities compared to that of patient priorities has been documented extensively in other areas of research.(10) This underscores the importance of ascertaining patient and family perspectives directly, rather than

attempting to anticipate the needs of this vital stakeholder group.(45) In order to gain accurate insights on the perspectives and priorities of patients and family on accelerated discharge planning from ICU, forums of discussion must be provided to shed light on the lived experiences and contextual factors that shape their opinions.

Understanding patient and family perspectives of accelerated discharge planning in the critically ill will engage patients as partners and provide a foundation from which to integrate and develop accelerated discharge planning protocols that consider the perspectives of a broader group of stakeholders (clinicians and healthcare service providers, *and* patients and families). This will enable a structured and evidence-informed approach to accelerated discharge planning, which will facilitate safe, coordinated, and effective transitions in care.

1.2.5 Knowledge Gaps

To our knowledge, there are currently no studies evaluating patient and family perspectives of accelerated discharge planning from ICU. Though a body of literature exists for family perspectives on accelerated discharge planning from NICU, including informational, emotional, and practical experiential needs to enhance readiness, the findings cannot be assumed to be generalizable to the adult ICU setting due to the differing nature of the patient population, informational needs required, the patient-family relationship, and potential differing priorities of accelerated discharge planning.(36,39,46,47) As such, the study presented in this thesis aims to address this knowledge gap using a sample of former ICU patients and former ICU patients' families in Canada.

1.2.6 Study Methods

Given the knowledge-gaps in the literature, inductive nature of this project, need for triangulation, and the focus on qualitatively exploring patient- and family-identified perspectives followed by quantitatively presenting patient and family priorities in accelerated discharge planning to facilitate safer transitions in care, sequential exploratory mixed-methods (QUAL→ quan) were most appropriate to address the objectives of this study. The theoretical paradigm underpinning the mixed-methods project is pragmatism, (48) which emphasizes a real-world practice orientation and the production of actionable knowledge. Given the need to integrate the perspectives of various stakeholder groups into a thoroughly informed, robust accelerated discharge planning protocol, the emphasis on actionable knowledge is fundamental. This sequential exploratory mixed-methods project is a subproject nested in a larger Patient and Family Caregiver-Oriented Transitions in Care CIHR Team Grant (NPA, Fiest).

As with all sequential explanatory mixed-methods studies, the qualitative segment of the study will be completed first and will inform the development and execution of the quantitative survey segment. Due to the impact of the COVID-19 pandemic and consequent research disruptions causing recruitment delays, this sequential exploratory mixed-methods project has been sub-divided into two studies, wherein the qualitative phase will be regarded as its own project and is the study reported in Chapter Two. The quantitative phase will be executed following the qualitative phase. Results from the qualitative and quantitative phases will be integrated in the third phase that connects the qualitative and quantitative data (**Figure 1**).(49)

The first phase of the mixed-methods project was a qualitative descriptive semi-structured interview study employing reflexive thematic data analysis. The foundational qualitative descriptive study design (50) is appropriate for the qualitative phase of the larger mixed-methods study as it is ideal when exploring perspectives on poorly understood phenomenon and/or when seeking to develop and refine questionnaires.(50) Given the novel nature of accelerated discharge model and consequent lack of prior work exploring patient and family perspectives on the practice of accelerated discharge *planning* in addition with the goal to develop a survey tool for the subsequent phases of the exploratory mixed-methods project, both of the aforementioned criteria for qualitative descriptive study designs are satisfied. Reflexive thematic analysis was deemed to be most reasonable for two reasons: i.) thematic analysis supports the exploration of shared meaning within the data which is aligned with the objectives of the project, and ii.) practicing reflexivity, and leveraging an analysis technique with researcher reflexivity at the forefront, supports the rigor of qualitative research and transforms subjectivity from a potentially problematic issue to a valuable tool promoting depth of analysis.(51) Given the knowledge gaps in the literature, the researchers deemed applying a theoretical framework not prudent for fear of incongruence and opted to use a more inductive approach to analysis with an experiential qualitative lens to enable theme development to be data-driven and encapsulating of individuals' own experience, respectively.(51)

1.3 Aims and Objectives

The overarching aim of this thesis was to explore patient and family perspectives on accelerated discharge and accelerated discharge planning. The primary objectives of this study were to:

i). Explore patient and family perspectives on the practice of accelerated discharge planning from ICU; and

ii.) Understand potentially supportive elements for patients and family to be included in accelerated discharge plans.

The secondary objective of this study was to understand patient and family perceptions of facilitators and barriers to accelerated discharge planning in Canadian ICUs. By satisfying our objectives we are enabled to conduct the quantitative phase of the larger mixed-methods project and generate a list of elements to include in accelerated discharge planning to be prioritized by patients and family.

CHAPTER 2: UNDERSTANDING PATIENT AND FAMILY PERSPECTIVES OF ACCELERATED DISCHARGE PLANNING IN THE CRITICALLY ILL: A QUALITATIVE INTERVIEW STUDY

2.1 Abstract

Background: Accelerated discharge, which involves *initiation of discharge planning earlier in patients' intensive care unit (ICU) stay*, has become more common to reduce discharge delays. Successful accelerated discharge planning relies on effective clinician communication and partnering with patients and family caregivers, who are the only constant throughout the care journey. To best enable family caregivers to feel self-efficacious in collaborating in the care of their critically ill loved one, their perspectives on the practice of accelerated discharge planning are needed to help facilitate successful transitions in care. This study sought to understand patient and family perspectives on accelerated discharge planning as well as their insights on supportive elements in accelerated discharge plans.

Methods: We conducted ~45-minute virtual semi-structured interviews with former critically ill patients and family caregivers of former critically ill patients between October 2021 and January 2022. We used inductive, reflexive thematic analysis to identify relevant themes and subthemes.

Results: Key themes identified following thematic analysis from seven participants (n=2 former critically ill patients, n=5 family caregivers) included: discharge planning process and stakeholder goal alignment (i.e., benefits of earlier planning, communication and continuity of care, and desire for stakeholder collaboration in care), patient and family support needs in accelerated discharge planning (i.e., informational support, psychological support, and logistical support), scope of support across care settings (i.e., form and timing of supports), individuality of dyads (i.e., condition, capacity, and

environmental characteristics specific to each dyad), facilitators and barriers to accelerated discharge planning at the individual and structural level.

Conclusion: The concept of accelerated discharge planning elicits positive regard from former critically ill patients and family caregivers through alignment of objectives between this transition in care model and patient and family goals of care. Individualized, realistic accelerated discharge plans that provide informational, psychological, and logistical supports may help facilitate successful transitions in care.

2.2 Introduction

The discharge of intensive care unit (ICU) patients to less acute clinical environments (e.g., hospital ward, rehabilitation facility, or community) is among the most challenging, high-risk, and inefficient transitions in care.(8) Conventionally, planning for discharge was initiated upon *stabilization* of acute illness, and patients transitioned to progressively lower-intensity care teams and locations before discharge into the community.(2,3) This model for ICU discharge may not be feasible in the long-term due to ongoing capacity strain issues (11) from increasing volume of ICU admissions and decreasing ward bed availability.(4) Technological improvements in patient monitoring, care delivery, and communication have enabled alternative transition in care models for some lower-risk (e.g., overdose, withdrawal, seizures) ICU patients. This includes accelerated discharge to ward and/or direct discharge into the community, wherein planning for discharge occurs upon ICU *admission*. Accelerated discharge planning seeks to facilitate safer, more efficient, and better coordinated transitions in care while reducing overall length of stay and subsequently lowering cost of care.(41)

Successful accelerated discharge planning relies on two critical pillars: 1) effective coordination between clinicians; and 2) partnering with patients and family caregivers (herein known as 'family'; i.e., family or friends who provide physical, mental, or emotional support to the patient). Effective coordination between clinicians has been the primary focus in studies to date; research must shift the focus to be inclusive of patients and families to ensure relevant perspectives are not missed.(2,8) Patients and families are the only constants during transitions in care and family caregivers are often key advocates for the patient.(9) Due to families' key role in transitions in care, ICUs

must ensure supports are in place to prepare dyads (critically ill patients and their family) to become active partners in accelerated discharge planning. Thus, to address this knowledge gap, this foundational qualitative interview study aimed to: 1) explore patient and family perspectives on the practice of accelerated discharge planning from ICU, and 2) understand potential supports for patients and family to be included in accelerated discharge plans. The secondary aim was to understand patient and family perceptions of facilitators and barriers to accelerated discharge planning in Canadian ICUs.

2.3 Methods

2.3.1 Study Design

This qualitative interview study was the first phase of a larger sequential exploratory mixed-methods project, underpinned by a pragmatic paradigm, exploring patient and family perspectives on accelerated discharge and priorities for accelerated discharge planning from ICU (**Figure 1**). For the current study, we used a qualitative descriptive study design (50) with data collected from semi-structured interviews with former critically ill patients and family of former critically ill patients. A qualitative descriptive approach was most appropriate for this study because we sought stakeholder insights on a novel discharge practice.(50) This study was reported in accordance with the Consolidated Criteria for Reporting of Qualitative Research (COREQ) checklist (**Appendix 1**).(52) The Conjoint Health Research Ethics Board at the University of Calgary approved this study (REB21-0211).

2.3.2 Study Sample

2.3.2.1 Selection and Recruitment of Participants

We used a convenience sample of eligible participants recruited face-to-face through the ongoing Activating family Caregivers in The Identification, preVention and mAnagemenT of dElirium (ACTIVATE) (53) study and virtual contact avenues including: i) existing networks, ii) the Alberta SPOR SUPPORT, and iii) social media (i.e. Twitter) (**Figure 2**). We intended to use a purposeful sample to representation of gender, socioeconomic status, and ethnicity in Canada, however the COVID-19 pandemic hindered recruitment efforts; thus, we revised our sampling protocol to permit less restricted participation.

2.3.2.2 Eligibility Criteria

To be eligible, former critically ill patients and family of the former criticality ill patients must have met the following criteria: aged $\geq$18 years, able to speak and read English, able to provide informed consent, and be residents of Canada. In addition, former critically ill patients must have: had a reason for ICU admission associated with a low chance of mortality (e.g., overdose, withdrawal, seizures, or metabolic coma)(4), received <96 hours of invasive mechanical ventilation, had an ICU stay between two and 10 days, and not left ICU or hospital against medical advice. These criteria (4,6,35) were to ensure we recruited participants that may have been eligible to safely undergo accelerated discharge from ICU.

2.3.3 Semi-Structured Interview Guide

A multidisciplinary research team (graduate student (EES), doctoral student (SJM), senior research associate (KDK), psychiatric epidemiologist (KMF), and

qualitative research expert (JPL)) drafted a semi-structured interview guide informed by previous qualitative experience within our group and relevant literature.(8,54,55) Draft semi-structured interview guides were presented to a patient partner (SK), critical care physician and member of the research team (HTS), and research associate (RP) for review of content and flow. A revised interview guide then incorporated suggestions for refinement and was pilot tested with the patient partner (SK) to assess face validity (for patient partner perception of interview question relevance to study objectives and interview guide flow); changes were made based on this assessment and no further edits were required (**Appendix 2**).

2.3.4 Data Collection

The researcher, EES, is a white, upper-middle class, cis-gender woman with a background in organizational behaviour emphasizing stakeholder-centric interventions. Consequently, in concert with findings from published transition in care literature (54–56), the researcher held the belief that, generally, patients and family would positively view a patient-oriented practice. However, the researcher was mindful of her preconceived notions and worked to remain neutral in all interviews to discourage social desirability bias arising from participants.

Demographic information was collected at the beginning of each interview. Videoconference (via Zoom) interviews were conducted by EES who has experience in qualitative methods and conducting semi-structured interviews. Rapport was established between the interviewer and participants via email correspondence pre-interview. Two days before each interview, participants were sent information about the study objectives and consent forms. Informed consent was obtained by the research

team prior to the start of each interview. All interviews were conducted within 45-minutes, audio recorded, transcribed verbatim using Rev.com, manually de-identified by research assistants (KP, LH), and imported to NVivo-12 (QSR International, Melbourne, Australia) for data management and analysis.

2.3.5 Data Analysis

Demographic data were analyzed using descriptive statistics. Qualitative data analysis was conducted concurrently and iteratively using the six-phase reflexive thematic analysis approach proposed by Braun and Clarke to explore shared meaning in the transcripts.(51) We used an inductive approach with an experiential qualitative framework to enable theme developments to be data-driven and encapsulating of individuals' own experience and implicit and explicit perspective, respectively.(51) Two researchers (EES, KDK) familiarized themselves with the data prior to systematic and independent coding. Once initial codes were developed, the researchers met to collaboratively discuss and organize codes, generate initial candidate themes, and subsequently collate coded data in the transcripts into candidate themes. Researchers met weekly over three weeks to develop, review, and refine themes. The final report encompassed the implicit and explicit perspectives of former critically ill patients and family caregivers on accelerated discharge planning from ICU.

Two researchers analyzed the dataset to develop richness of understanding of participant perspectives. Rigor was established by addressing credibility and trustworthiness by leveraging member checking (i.e., final copy of themes/subthemes to two participants [n=1 former critically ill patient and n=1 family caregiver] for review and comment), dependability through an audit trail and iterative meetings to establish codes,

and by keeping reflexive journals to reflect on researcher assumptions, to prevent

confirmation bias by being cognizant of researcher characteristics that may impact data

interpretation, and acknowledge the inherent subjectivity in analysis.(51)

2.4 Results

2.4.1 Participants

We conducted six interviews between October 2021 and January 2022

accounting for seven participants (n=2 former critically ill patients, n=5 family) (**Table 1**).

Participant recruitment is reported in **Figure 2**. Participants' demographics are reported

in **Table 1**. All participants were involved with discharge to a less acute clinical

environment in hospital prior to discharge home in the community.

2.4.2 Participant Experience of ICU

Participants described their experience in ICU as highly "traumatic" (former

critically ill patient 2[**P2**]), "distressing" (family 5 [**F5**]), and "overwhelming"(**F3**).

Participants noted that much of their distress stemmed from a perceived lack of

communication between clinicians and the dyad(**P2**,**F5**). Upon discharge from ICU to a

less acute clinical environment, despite discharge being a "good sign" (**P2**) signaling

recovery, participants noted that they were worried due to the "[lesser] level of scrutiny

and observation…" (**F4**) compared to that in ICU. Upon discharge to home in the

community, participants described feeling unease and fear from not knowing how to

respond to difficulties related to the patient's condition (**P1**). We present quotations of

participants' ICU experience in **Table 2.**

2.4.3 Perception of Accelerated Discharge Planning

Five themes related to patient and family perspectives on accelerated discharge planning in the critically ill were identified in the data: (1) Discharge planning process and stakeholder goal alignment; (2) Patient and family support needs in accelerated discharge planning; (3) Scope of support across care settings; (4) Individuality of dyads; and (5) Facilitators and barriers to accelerated discharge planning. We present quotations within the text and **Table 3** to support each theme.

Discharge Planning Process and Stakeholder Goal Alignment

The theme *discharge planning process and stakeholder goal alignment* refers to the alignment of objectives between accelerated discharge planning and patient and family goals of care. When participants were asked about their perspectives on the process of accelerated discharge planning, researchers identified sub-themes of i) *benefits of earlier planning*, ii) *communication and continuity of care*, and iii) *desire for stakeholder collaboration in care.*

Benefit of earlier planning

Many participants noted benefits of initiating planning earlier in ICU care that researchers organized into two categories: logistic and cognitive benefits. Logistically, participants noted the benefit of having lead time to be able to appropriately prepare for eventual discharge from hospital (**F4**) and mobilize relevant entities to support discharge (**F5**). Cognitively, by initiating planning earlier, perceptions of the discharge operations within ICU would be better regarded and hope for healing would be fostered (**P2**).

Communication and continuity of care

Most participants perceived a lack of communication between clinicians and dyads while in ICU, resulting in a burden of uncertainty on the dyad (**P2**). All participants expressed the anticipated benefit of increased communication and rationale (**P2**) around care and discharge planning so that dyads could understand care operations, anticipated trajectory of care, and their role in accelerated discharge planning. Some participants elaborated by connecting the role of increased planning communication between stakeholders and positive impact on continuity of care across settings (**F5**).

Desire for stakeholder collaboration in care

Participants expressed desire to be active collaborators in care planning decisions to support patient advocacy and more optimal outcomes through multi-perspective collaboration (**P2**,**F5**). Beyond supporting stakeholder-centric care decisions (**F5**), family expressed a desire to be involved as stewards of care in and after ICU (**F1**).

<u>**Patient and family support needs in accelerated discharge planning**</u>

When asked about the types of supports dyads would need in accelerated discharge planning, sub-themes related to: i) *informational support*, ii) *psychological support*, and iii) *logistical support* needs were identified.

Informational supports

All participants expressed informational support needs in accelerated discharge planning. We defined informational supports as resources that provide knowledge/fact to facilitate dyad understanding. While in ICU, participants expressed the need for "a roadmap for ICU" to explain the patient's diagnosis and anticipated care journey in a clear, simple manner (**F3**). Informational supports in ICU were an expressed need to

enable mental preparation of the future, an understanding of "where their family fits in that picture of things" (**F3**), and help facilitate dyad planning decisions (**F3**).

Once discharged back into the community, family expressed need for a discharge packet that includes informational supports such as a "check-list" (**F2**) or home-care plan that includes resources for additional informational support (i.e., "discharge [phone] line" (**P2**), websites, first aid kit) to enable the family to feel empowered in caring for the discharged patient (**F4**) and prevent unnecessary visits to the emergency department in an effort to seek support (**P1**).

Psychological supports

Most participants expressed psychological support needs in accelerated discharge planning. We defined psychological supports as resources that assist dyad mental wellbeing. Participants suggested that bolstering dyad readiness for accelerated discharge planning is important and could be facilitated through psychological validation from the clinical team that accelerated discharge is an appropriate choice for the patient that would facilitate the care objectives for the patient (**P2**).

Once discharged into the community, participants expressed the need for psychological supports in the aforementioned hypothetical accelerated discharge packet, including affirmations of the physical and mental toll that an ICU experience may cause and to expect a mental and emotional refractory period (**P2**). Further, mental health resources (e.g., helplines, community support groups) were recommended for inclusion in an accelerated discharge packet to help process the experience and prevent lingering trauma (**F2,F4**).

Logistical supports

Some participants also addressed logistical supports needs in accelerated discharge planning. We defined logistic support as elements that facilitate the overall process of how resources are acquired (e.g., *delivery* of information, *acquisition* of medications). Central to logistical supports is the notion of "making sure the [family] isn't left in a position where they're being pushed to accept a patient they don't have the right supports for yet" (**F5**). Family perceived it was unfavourable to leave their patient unattended when recovering from critical illness and consequently expressed worry of having to leave the critically ill patient both in hospital and initially upon return home. Participants suggested that logistical supports be considered in accelerated discharge planning so the family can successfully manage their role as caregiver by being well-positioned throughout the patient recovery process. In ICU, participants expressed the need for information being physically provided in an accessible manner (i.e., lay and clear information, in dyad's primary language) that was compatible with family remaining at the bedside (e.g., ICU tablets, binders). Upon discharge into community, participants expressed the need for logistical supports, such as pharmacy deliveries (**F2,F4**), so the family would not jeopardize patient safety by leaving them unattended in the initial days at home (**F5**).

Scope of support across care settings

We defined scope of support across care settings as the variable form and timing of dyad supports across settings. While informational, psychological, and logistic support are needed across care settings, the actual form of the support may differ (e.g. informational care roadmap in ICU versus home-care plan information once in community). Priority of the various supports may also change across care settings and

with time (e.g., psychological supports not needed for patient until well after discharge into the community [**P2**]).

Another consideration participants raised was the need for "follow-up calls" (**F2**) in accelerated discharge planning once the patient is back in the community. Participants suggested the onus to initiate follow-up should be on healthcare professionals, warning that patient/family-initiated follow-up may not occur for a myriad of reasons (**F2**).

Individuality of dyads

We defined individuality of dyads as the condition, capacity, and environmental characteristics specific to each dyad. Participants emphasized the importance of patient-oriented considerations when building accelerated discharge plans to ensure both feasibility and suitability to the wishes of the dyad (e.g., care goals) (**F5**). Individuality of dyads also included the concept that resources (i.e., links/contacts) are curated to the dyad's unique situation (e.g., resources specific to patient condition, dyad's geographical location, and home physical environment [home retrofitting needs, if applicable]) (**F5**) as opposed to more generalized information and supports which may cause confusion and misinformation (**F3**).

Facilitators and barriers to accelerated discharge planning

At the individual-level, participant-identified facilitators to accelerated discharge planning included curated supports provided and available to dyads (**P2**). At the structural-level (defined as the aspects of ICUs, hospitals, or healthcare that direct rule, responsibilities, and roles), participant-identified facilitators to accelerated discharge

planning included leveraging a designated transition manager/liaison to support care across settings (**F4,P2**).

At the individual-level, participants suggested that one barrier to accelerated discharge planning would be dyad resistance resulting from (mis)interpretations of the phrase "accelerated discharge" and consequent (mis)conceptions around the purpose of the practice. Participants suggested that the name "accelerated discharge" may "sound like you're being…pushed out too soon" (**F3**). To mitigate this, participants emphasized the importance of ensuring dyad understanding that accelerated discharge is a "patient-centered care" (**P2**) practice and not an "administrative… or hospital-centered" (**P2**) push. Other individual-level barriers to accelerated discharge planning were dyad considerations limiting the family's ability to be a caregiver (i.e., financial constraints [**P1**], living in different cities [**F3**]).

At the structural-level, participant-identified barriers to accelerated discharge planning included hospital staffing availability (i.e., clinician capacity to collaborate with dyads [**F4**]), ICU inaccessibility for family (i.e., time demands to be granted visitation access [**F1**]), and inaccessibility of resources (i.e., phone support only accessible during work hours [**F3**]).

2.5 Discussion

Former critically ill patients and family perceive the practice of accelerated discharge planning to be beneficial and aligned with their goals of care. Pending appropriate and accessible supports are provided, there will likely be patient and family buy-in for the practice of accelerated discharge from ICU. The supports required for dyads in accelerated discharge plans include informational, psychological, and logistical

with the exact nature and timing of supports varying across care settings. Further, it is important that these supports, as with accelerated discharge plans, are individualized to meet the unique needs and circumstances of the patient and family dyad.

Accelerated discharge planning may provide patients and families with opportunities missed in other ICU discharge models. op 't Hoog found that family wanted to be more involved in discharge planning to step-down-units from ICU.(54) Similarly, Forsberg found that patients desired to be involved with planning for transfer out of ICU to facilitate feelings of control during the transfer process.(55) Taken together, these studies suggest that patients and families want more involvement in discharge planning from ICU.(54,55) Our study suggests patients and families are receptive to accelerated discharge planning because it elicits increased dyad-clinician communication and collaboration on discharge planning from ICU.

The support needs for patients and family in accelerated discharge planning are consistent with the needs reported in the broader transitions in care literature. Informational supports have been found to be a patient and family need in ICU (57) and to support transitions across care settings.(55,56,58,59) Häggström found that 53% of family members reported perceptions of inadequate support after ICU discharge and cited information needs as important to family.(56) Similar to our finding that informational supports are needed in accelerated discharge planning to facilitate the role of families as self-efficacious caregivers through care settings, Herling suggests that information is a key factor in bolstering patient and family empowerment in and beyond ICU.(59) Häggström, found that reassurance was important for family in ICU discharge plans which is consistent with our finding of validation needs within the theme

of psychological supports in discharge plans.(56) Recommendations put forth to support

discharge planning from neonatal ICU suggest that emotional, educational, and pre-

and post-discharge resource coordination support, with specific emphasis on follow-up

care for infants discharged earlier from neonatal ICU are important considerations in

discharge planning.(47) Our study in adults similarly found that psychological,

informational, and logistical supports are important considerations in accelerated

discharge plans from adult ICU and that follow up supports are an important provision in

the accelerated discharge planning scope of care.

Strategies for individualizing discharge plans have been proposed to support

improved patient outcomes in transitions in care (60), with patient-oriented discharge

summaries (PODS) as one such innovation.(61) Similarly, in our study, patients and

family suggested accelerated discharge plans be collaboratively designed with the

individual characteristics of the patient and family in mind to generate plans that are

comprehensible (i.e., offered in dyad's language and education level), feasible for

patient and family to successfully follow (i.e., family participation demands aligned with

their capacity to be involved, relevant supports provided if needed), and aligned with

their goals.

The strengths of this study include that the development of the semi-structured

interview guide which was informed by research on ICU discharge planning (8,54,55)

and co-designed, piloted, and refined by a multi-disciplinary team. Semi-structured

interviews were conducted individually which allowed for the time and psychological

safety needed to reflect on experiences in ICU and resulting perspective on accelerated

discharge planning. Reflexivity of researchers was practiced (e.g., reflexive journaling

throughout, researcher reflexivity statement), an extensive audit trail was maintained, and member-checking was leveraged to facilitate credibility of findings. However, there are also limitations to this study. Due to the COVID-19 pandemic, many potential participants were ineligible (e.g., invasive mechanical ventilation exceeding 96 hours). Thus, we deviated from the intended purposeful sampling in favour of convenience sampling that precluded any exploration of the association of sociocultural factors on perceptions of accelerated discharge. While themes were consistent across participants and there was considerable "information redundancy" (62,63), thematic saturation was not reached likely due to the limited sample size. However, as this was a foundational study, the themes identified provide a relevant starting point for future research.

2.6 Conclusions

Former critically ill patients and family positively view accelerated discharge planning, as the objectives of this transition in care model are aligned with patient and family goals of care. Individualized, realistic accelerated discharge plans that provide informational, psychological, and logistical supports will help facilitate successful transitions in care. Continued research with a larger and more diverse sample is warranted when conducting the quantitative phase of the larger mixed-methods project that aims to prioritize support elements for dyads in accelerated discharge plans.

2.7 Abbreviations

ACTIVATE: Activating family Caregivers in The Identification, preVention and mAnagemenT of dElirium

AD: Accelerated discharge

APACHE-II: Acute Physiology and Chronic Health Evaluation II

CHREB: Conjoint Health Research Ethics Board

CIHR: Canadian Institute of Health Research Reporting of Qualitative Research

COREQ: Consolidated Criteria for

F: Family caregiver of former critically ill patient

ICU: Intensive care unit

IQR: Interquartile range

P: Former critically ill patient

PICS: Post-intensive care syndrome

PODS: Patient-oriented discharge summary

QUAL→quan: Sequential exploratory mixed methods

SCNs: Services' Strategic Clinical Networks

2.8 Declarations

Ethics approval and consent to participate

This study (REB21-0211) was approved by the University of Calgary Conjoint Health

Research Ethics Board (CHREB). A waiver of consent was obtained from the ethics

review board.

Consent for publication

Not applicable.

Availability of data and materials

The data analyzed in the current study are not publicly available due ethical concerns

but are available from the corresponding author on reasonable request.

Competing interests

There are no declared conflicts of interest from any of the contributing authors.

Author contributions

EES, KMF, JPL, and HTS were involved in acquiring study funding. All authors were involved in study design. EES and KDK completed data analysis. EES drafted the initial manuscript, and all authors critically revised, read, and approved the final manuscript.

2.9 Figures
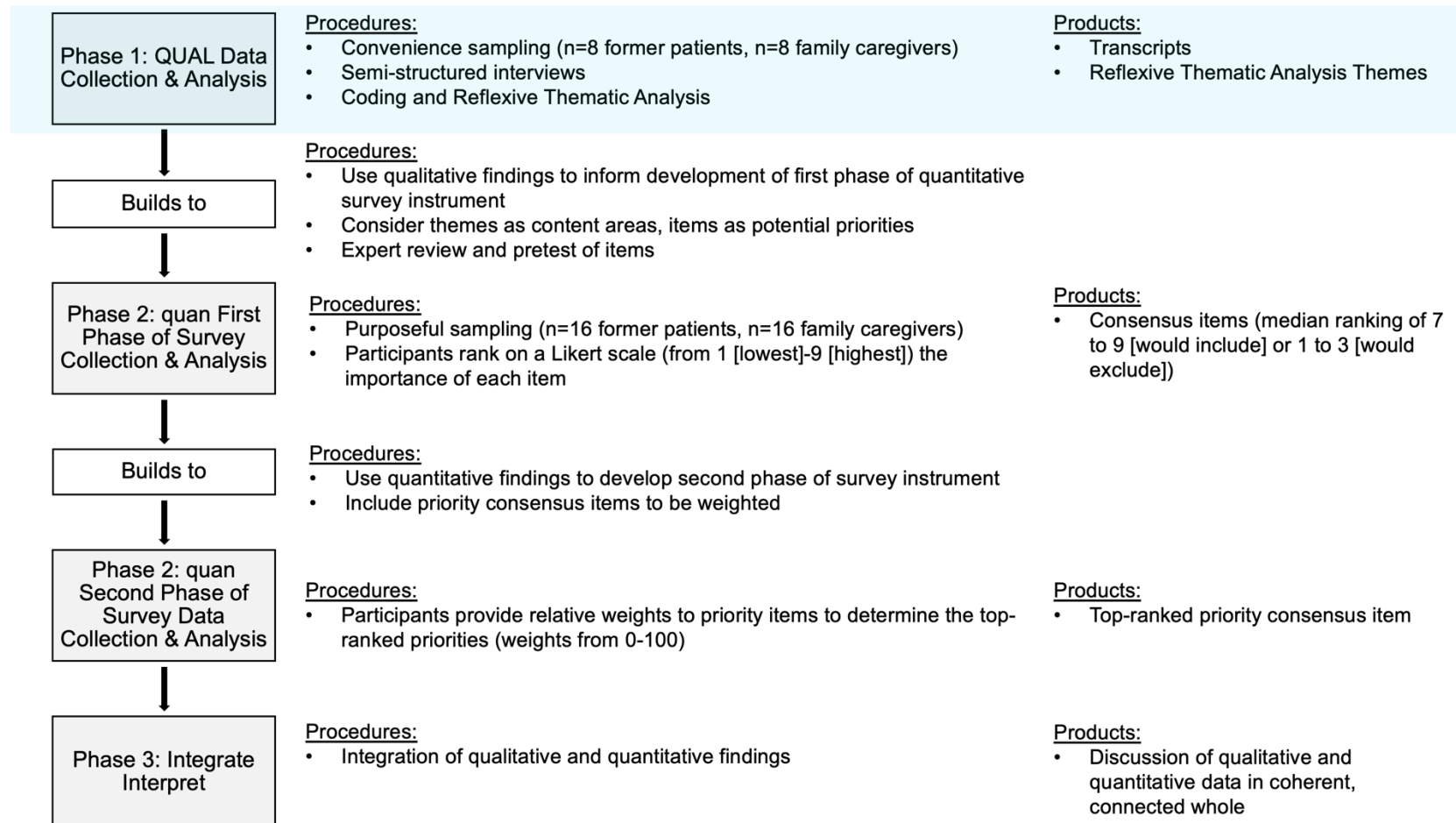
Figure 1. Sequential exploratory mixed methods (QUAL→ quan) flow diagram, highlighted component presented in

Chapter 2
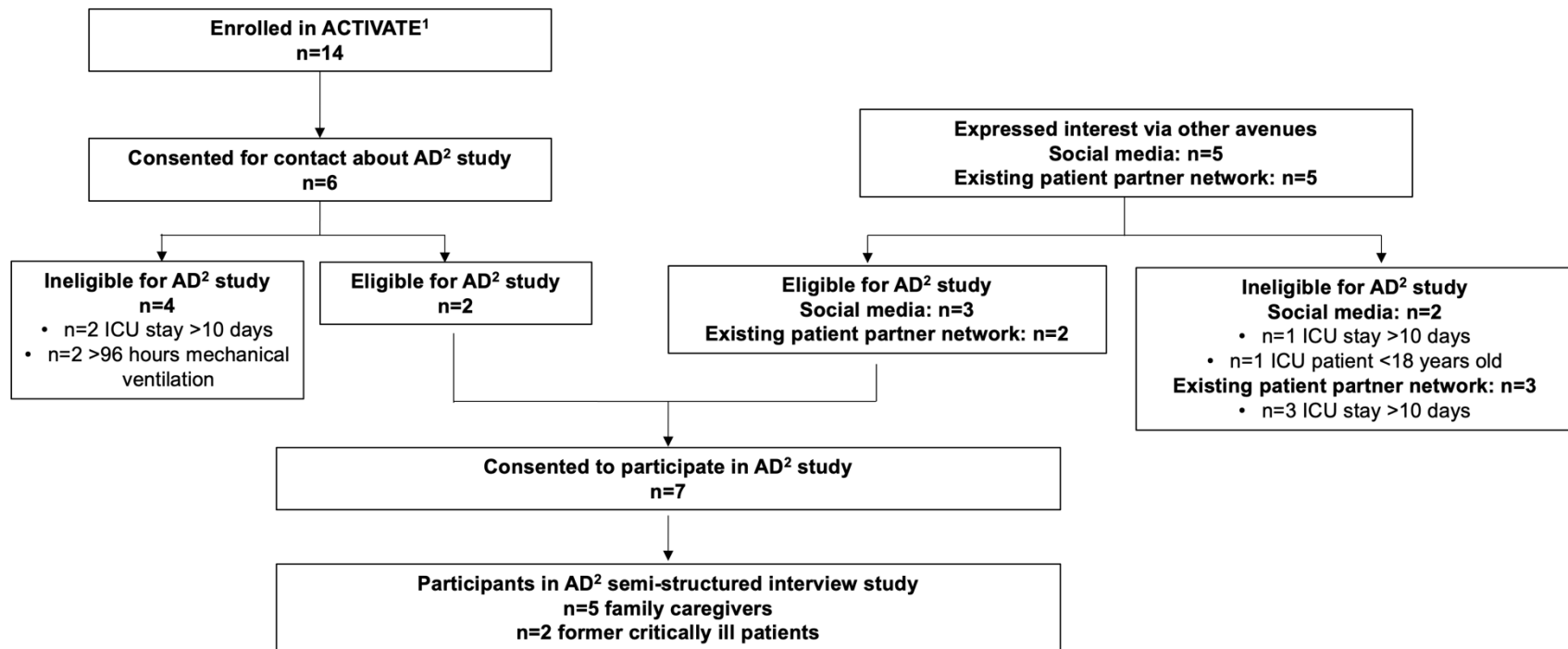
Figure 2. Study flow diagram

[1]:Activating family Caregivers in The Identification, preVention and mAnagemenT of dElirium

[2]: Accelerated Discharge

2.10 Tables

Table 1. Participants Characteristics

Demographic	Family (n=5)	Critically Ill Patient (n=2)
Age category, years, n(%)		
18-29	0(0)	0(0)
30-39	0(0)	1(50)
40-49	1(20)	0(0)
50-59	2(40)	1(50)
≥60	2(40)	0(0)
Sex[1], n(%)		
Male	0(0)	1(50)
Female	5(100)	1(50)
Gender[2], n(%)		
Man	0(0)	1(50)
Woman	5(100)	1(50)
Province[3], n(%)		
British Columbia	1(20)	0(0)
Alberta	4(80)	2(100)
Saskatchewan	0(0)	0(0)
Manitoba	0(0)	0(0)
Ontario	0(0)	0(0)
Quebec	0(0)	0(0)
Nova Scotia	0(0)	0(0)
New Brunswick	0(0)	0(0)
Newfoundland & Labrador	0(0)	0(0)
Territories (Northwest Territories, Nunavut, and Yukon)	0(0)	0(0)
Relationship to patient, n(%)		
Spouse	2(40)	-
Adult Child	1(20)	-
Parent	1(20)	-
Cousin	1(20)	-

[1]As recorded at birth
[2]As reported at time of semi structured interview
[3]As recorded at time of semi structured interview

Table 2. Perspectives of Former Critically Ill Patients and Family of Former Critically Ill

Patients on Their ICU and Discharge Experience

Participant	Exemplar Quote
F1	"It's so loud and there's so many machines going off that most people are really overwhelmed, and they're just kind of like in this stunned state in there."
F2	"I didn't understand what was going on with [critically ill patient]. There was really not a lot of information given to us."
F5	"[ICU] was very, very distressing; and it was distressing in the way that there was a lack of communication partially, and there were misunderstandings about what [the patient] should be doing…."
F4	"[Upon discharge to ward, I was] worried because all of a sudden you don't have the same level of scrutiny, and observation…"
F3	"…You feel very special in ICU because you do get such good care and then you feel like nobody cares after."
P1	"I was terrified when I came home. Imaging coming home to my beautiful wife, my family, you know a part of me, 50% of me didn't want to go home…I was scared. Like what if [family caregiver] doesn't know how to do something? But at the hospital you could just hit the doorbell and have four doctors in front of you."

Table 3. Perspectives of Former Critically Ill Patients and Family of Former Critically Ill

Patients on Accelerated Discharge Planning in the Critically Ill

Theme/subtheme	Exemplar Quote
Discharge planning process and stakeholder goal alignment	
Benefit of earlier planning	"Well, that you know, no lead time, that's a big one. You know get preparing…Once they're discharged from ICU to a medical ward, then you know that they're coming home pretty darn quickly probably, or even if they're discharged right from ICU to home, there are things to get ready, like if there's a mobility issue or food because you don't want to leave them and go get groceries if you've just gotten home. So, I think communication and lead time." (F4)
	"Well, it'd be any patient going home to the community that they want to call home, in an accessible home with the right support…I believe that when you wait to put in supports, when it is almost discharging, you've missed so many opportunities to get the right people involved." (F5)
	"[Accelerated discharge] would translate to patients not feeling like it's a scrambly decision but feeling like it's being talked about. And I think, depending on the certainty of discharge and how it's communicated, it could help build hope for patients because they will not feel like, "What's going to happen to me?" They'll feel like they're headed in a direction of healing and rehabilitation." (P2)
Communication and continuity of care	"I think one of the things when you're in the hospital for that long and you're going through a traumatic experience is that the waiting and then not knowing is the hardest part." (P2)
	"Using layperson language…communicating [care and discharge plans] in a way that's understandable, clear, broken down into language that's like, "Okay, we are moving you from here to here. And this is why." Rather than the terminology itself." (P2)
	"And so, that lack of communication really stems all the way around to what's in the best interest of the patient, and is the whole team working together? And when you're not working

together, this is where breaks happen, and gaps happen. And this is how people die." (F5)

Desire for stakeholder collaboration in care	"Having a family member advocate for you and your care and be able to be cognizant and understanding, a huge facilitator. I would've had no idea what was going on and probably exponentially more scared if my mom and my dad and partner at the time weren't there." (P2) "To give the patient more of a voice of whatever that future looks like with the right connections and the right voices at the table…[patient and family inclusion in decision making] adds to the multi perspectives, which ultimately adds to the better outcome for patients with that wrap around support." (F5) "The nurses were very supportive as were all the doctors and they were very encouraging, and they were awesome. I was really grateful that they allowed me to do my job as a physio." (F1)

Patient and family support needs in accelerated discharge planning

Informational needs	"I think, when you get admitted, there should be a leaflet. Everybody doesn't take it all in, but they've got a lot of time to sit around, might as well be reading something or looking at it online something in the form of, "This is how this unit works, and at some point, these things will happen. Some of these things will happen or some of these will happen and so people have the big picture. I'm all about the big picture in the world, because how do you make the smaller decisions if you don't know what the big picture is? You get off on a tangent, and it can get you in trouble. So, if you have the big picture when they first go in, you have a better idea what's going to come in the next little few days, week...." (F3) "I think you know when the patient gets home out of ICU, they're pretty freaked out. So if the caregivers can be reassuring in saying, "We've got a plan here, and this is what we were going to expect, and we've got a phone number to call if we need." (F4) "I was worried about what is okay, what level of being out of breath is okay, how is she doing in terms of getting stronger

and how do we know? So a helpline would've been great…"
(F4)

"A lot of times you're going to come to [the emergency department] for nothing, because the family's just scared, you know?" (P1)

Psychological needs	"Like, "We're working on an accelerated discharge. This is why we think it could support you." Or, "This is why it's appropriate." And just communicating that so you know. And then maybe being told, "This is a good thing because it means we know you're going to make it through this and we want to get you onto that next stage of support, kind of bridging that care." (P2)

"And being in the hospital for even a week or eight days and being that sick feels like you're there for months. And so I think that, and I personally wanted to get back to normal life and jump into classes and do everything I was doing, but I couldn't, I didn't have the stamina, like the energy, I physically couldn't. And cognitively, emotionally couldn't right away. And some kind of supports that prepare you for that, because I think you can feel like, what just happened and shouldn't I be better? They didn't keep me in the hospital, but I'm here. Affirming that there's kind of a rehabilitation plan or emotionally and mentally a time period where you're going to need to recuperate from that experience. And I don't know what that would, I think it would be really individualized, I don't know if it would even be like, "In the weeks after this, some people experience X Y Z or you may find you're needing more rest and time to get into a routine or things you are doing. These are some help lines." Or, "These are some community resources that you could follow up with." (P2)

"Well, again, the helpline, and in hindsight, I think some kind of mental health resources would've been a phenomenal idea. Because as her caregiver, like for her, she was like, "Okay, I've been really sick, and I'm just tired, I've got to sleep or whatever." And I was freaked out, and in fact, when I talk about it, even 10 years later, I still get freaked out, well, not freaked out… but I still…I'm normally a very calm person, but I can still feel it affects me." (F4)

"Maybe there's a list of families that have been in ICU that want to talk and help other people, that they've gone through the same thing. And this is what they did to make that |

	acceleration better because it's experience and knowledge of people that have actually gone through it…. Who knows better than someone that's gone through that trauma?" (F2)
Logistical needs	"Meaning if they don't have a hospital bed, if they don't have a bed rail, if there's no shower handle, this is where that team based with OT and the connection between community home care and, and in hospital best facilitates, everything mean in place…Because if it's going to take three weeks to get these things in place and ordered to then go, "Oh. Yeah, you're getting out tomorrow or the next day. Is this stuff in place? Then is home care ready to add the home care services back?" Making sure the caregiver isn't left in a position where they're now being pushed to accept a patient they don't have the right supports for yet." (F5)
	"Pharmacy deliveries of medication, that kind of thing." (F2)
	"If they need a prescription, you know right when they leave, that's tricky. Again, because you're taking them home, but then you've got to find a drug store, so if there can be sort of like a...let's say a three day bubble pack given to patients and their caregivers to go home, bide them for three days until they can get settled, that would've been phenomenal." (F4)
	I can only tell you when you speak to caregivers, sometimes it's simple things that when you can't leave a complex patient at home, but you don't have someone to grab that thing you need, but you need something. How do you get what you need?" (F5)

Scope of support across care settings

	"I think an interesting thing about [ICU] experience… is that in the moment you are physically and mentally in a survival mode. So the openness and understanding of what's happening to you or to your family, it's just not there right away. And you're so much focused on moving from A to B, getting home, what's going to happen after? I think the mental health part really comes later…. Being given resources that you're not ready for or not able to use in the moment is one thing. And it is something, I think, even being validated, "Hey, you might find you want to hang onto these for a little bit from now so that you can make sense of this experience if, and when, you need."" (P2)

"And follow up calls. Big time. Because sometimes people, different cultures, different perspectives feel, "Oh I'm wasting their time kind of thing." Right?" (F2)

Individuality of dyads

"…[Understanding] that patient's head, hand, and heart. What are their hands physically capable of doing in their head? What does that patient really want? And in their heart, what does that patient really want? And working to help that patient achieve that." (F5)

"What could improve [discharge planning] is better communication, better ability to take a gander at what the patient could do, or would want to do, and what environments they were going into…How does that community care look like, and what does that community care look like? Because if any risk of a patient deteriorated in the community, it's making sure that the family is set up to manage the most tragic outcomes as quick as possible is like providing the families with the first aid kit that's individual to each family's need, based on what they might need." (F5)

"I think it would be really individualized, I don't know if it would even be like, "In the weeks after this, some people experience X, Y, Z, or you may find you're needing more rest and time to get into a routine or things you are doing. These are some help lines." Or, "These are some community resources that you could follow up with." (P2)

"I've seen discharge papers from hospitals, my own when I've had surgeries, other people's, and they are not very clear. There's a lot of words that don't pertain to you, or they do, but they say, "Don't worry about that." They point to, "Don't worry about that." "Why shouldn't I worry about that? Is that relevant to me? … and then there's some wild circles of stuff that's relevant to you, but it's a word I've asked people, "What does that mean?" And they'll say, "It doesn't really matter. It's just for when we discharge, we have to do that." Well, it does matter to me." (F3)

Facilitators and barriers to accelerated discharge planning

"If it was someone's job to facilitate discharges, that would be a dream. Just having brief meetings with people as they're leaving the ICU, and the nurses, they're so short staffed. The

doctors can't do it because they're in high demand, but some kind of a...I don't know maybe it would be a mental health, health specialist that understands the history or maybe it is a nurse, but somebody who can be that liaison, I think that would be phenomenal." (F4)

"A designated person, yeah, to follow up with … You want to feel like your care is connected." (P2)

"And follow up calls. Big time. Because sometimes people, different cultures, different perspectives feel, "Oh I'm wasting their time kind of thing." Right?" (F2)

"The name makes it sound like you're being punted early…."Accelerated planning for discharge," maybe there's a different way of saying that that makes people feel like they're not being pushed out too soon." (F3)

"There's a lot of families in there that had a tremendous amount of financial constraints around them. And they couldn't be in the hospital as much as they probably wanted to." (P1)

""Here's the resources," and they hand you some papers, and then you go home and then people only work during regular work hours, or they're on holidays, and you can't get ahold of any of those people, and you're like, "Well-" That was a waste of paper."… "What now?" Because that's their job, and they know they're only there during work hours, and you're supposed to have your problem when they're at work…. Well, that can happen three or four times," and you're like, "Well, what about where's my support?"" (F3)

2.11 Appendices

Appendix 1. Consolidated Criteria for Reporting Qualitative Studies (COREQ)

Domain 1: Research team and reflexivity	
Personal Characteristics	*Location, (page)*
1. Interviewer - Which author/s conducted the interview or focus group?	Methods, (20)
2. Credentials - What were the researcher's credentials? E.g. PhD, MD	Preface, (iv)
3. Occupation - What was their occupation at the time of the study?	Methods, (19)
4. Gender - Was the researcher male or female?	Methods, (20)
5. Experience and training - What experience or training did the researcher have?	Methods, (20)
Relationship with participants	
6. Relationship established - Was a relationship established prior to study commencement?	Methods, (20)
7. Participant knowledge of interviewer - What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods, (20)
8. Interviewer characteristics - What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods, (20)
Domain 2: Study design	
Theoretical framework	
9. Methodological orientation and Theory - What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods, (18, 21)
Participant Selection	

10. Sampling - How were participants selected? e.g. purposive, convenience, consecutive, snowball — Methods, (19)

11. Method of approach - How were participants approached? e.g. face-to-face, telephone, mail, email — Methods, (19)

12. Sample size - How many participants were in the study? — Results, (22)

13. Non-participation - How many people refused to participate or dropped out? Reasons? — N/A, none

Setting

14. Setting of data collection - Where was the data collected? e.g. home, clinic, workplace — Methods, (20)

15. Presence of non-participants - Was anyone else present besides the participants and researchers? — N/A, none

16. Description of sample - What are the important characteristics of the sample? e.g. demographic data, date — Results, (22)

Data collection

17. Interview guide - Were questions, prompts, guides provided by the authors? Was it pilot tested? — Methods & Appendix, (19-20, 47-53)

18. Repeat interviews - Were repeat interviews carried out? If yes, how many? — N/A, none

19. Audio/visual recording - Did the research use audio or visual recording to collect the data? — Methods, (21)

20. Field notes - Were field notes made during and/or after the interview or focus group? — Methods, (21)

21. Duration - What was the duration of the interviews or focus group? — Methods, (20-21)

22. Data saturation - Was data saturation discussed? — Discussion, (31)

23. Transcripts returned - Were transcripts returned to participants for comment and/or correction?	N/A, transcripts not returned

Domain 3: analysis and findings

Data analysis

24. Number of data coders - How many data coders coded the data?	Methods, (21)
25. Description of the coding tree - Did authors provide a description of the coding tree?	Methods, (21)
26. Derivation of themes - Were themes identified in advance or derived from the data?	Methods, (21)
27. Software - What software, if applicable, was used to manage the data?	Methods, (21)
28. Participant checking - Did participants provide feedback on the findings?	Methods, (21)

Reporting

29. Quotations presented - Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results & Table 3, (22-28, 38-43)
30. Data and findings consistent - Was there consistency between the data presented and the findings?	Results & Table 3, (22-28, 38-43)
31. Clarity of major themes - Were major themes clearly presented in the findings?	Results & Table 3, (22-28, 38-43)
32. Clarity of minor themes - Is there a description of diverse cases or discussion of minor themes?	Results & Table 3, (22-28, 38-43)

Appendix 2. Semi-Structured Interview Guide

Perspectives on Accelerated Discharge Planning from ICU **Introduction** Semi-structured interview guide

1. Introduction

*****If you find the interview is running long, emphasize probing over asking many questions*****

Interviewer introduction: My name is Em. I am Graduate Student in the Department of Critical Care Medicine under the supervision of Dr. Kirsten Fiest. Thank you for taking the time to participate in an interview that I am conducting as part of my graduate work.

Reminders: Before we begin the interview, I am going to review a few things. If you need a break during the interview to use the restroom, please tell me. As a reminder, we are not recording the video, only the audio.

Primary goal: The goal of this interview is to understand your perspectives on accelerated discharge planning. When I say accelerated discharge planning, I mean the process of when doctors and nurses work with the patient and family to plan for when the patient leaves the ICU. This accelerated discharge planning will begin when a patient is admitted to an ICU so to streamline care. This is a new idea because usually planning for discharge happens when a patient is ready to leave the ICU and this may result in delays

It is important to hear from patients and families about what things are important to them when considering accelerated discharge planning. You are the expert. There are no right or wrong answers to the questions I have for you. I am interested in learning about your experiences and perspective. We will focus on three areas:

> **Your perspectives on accelerated discharge planning:** Your experience with general ICU care and discharge planning from the ICU.

> **Beneficial elements to discharge plans:** Your suggestions about what should be included in an accelerated discharge plan.

> **Helpers and preventers to accelerated discharge planning:** Your ideas around what would make accelerated discharge planning easier and what would make it more difficult.

Recording: As I mentioned over email, we do not need to collect your signed consent for this interview. Before we start the interview I do want to revisit the oral consent form I had emailed to you

[READ CONSENT FORM}

start recording

2. *Verbal consent*

Now I would like to ask for your verbal consent. Would you like to participate in this interview?
  O Verbal consent was obtained from the study participant
  O Verbal consent was NOT obtained from the study participant

Do you permit me to record our interview?
  O The interviewee permitted recording
  O The interviewee did NOT permit recording **stop the recording, end the interview**

Do you have any questions before we get started?
  O The interview proceeded further
  O The interview did NOT proceed further

I am just going to capture some demographic questions first
- What is your age
- What is your sex
- What is your preferred gender
- What city/town do you live in
- What is your relationship to the former ICU patient (if not the patient)
- If you can recall, what was the duration of your ICU stay?

3. *Background information*

This is a conversational starter in order to put the participant at ease. We are trying to get a sense of their overall experience with accelerated discharge so we know if they have undergone this method or discharge or if discharge followed a traditional method

First, I would like to know a bit of background information about your general experience in ICU. Please think about your role as a patient or a family member. What was that experience like?
[PROBE:
  What are the comforting things about your experience?
  What are some of the distressing things about your experience?
  How could you have been better supported?]

It sounds like your experience in ICU was _____.

Now I would like to know whether you discharged to unit or directly home from ICU and what that experience was like?
[PROBE:

      What were you feeling when discharge occurred?
      How did the process seem to you?
      What could have been improved in your discharge experience?
      Did anything work really well?]

4. What matters to you?

We want to encourage a meaningful conversation with the participant. By asking what really matters, we can build trust, develop empathy, and understand the families. This simple question aims to reach the essence of person-centered care in a simple way. Ultimately, starting the interview with this question will improve the humanistic quality of the interview and the person-centered care that we may provide.

Before we begin with the three main areas of that I described earlier, I first would like to know, what matters to you today?
[PROBE:
      Is there anything specific that you would like us to talk about today?]

Please indicate below how the participant appears
This will aid in how the statements are analyzed regarding reflexivity and dissemination

      O The participant appears open to conversation and satisfied to start (positive)
      O The participant appears closed to conversation and dissatisfied to start (negative)

5. Perspectives on accelerated discharge planning

We can transition from S4 to S5 based on the response and the tone to S4. The participant will be most likely to talk about what is currently on their mind. So, if the participant appears open to conversation, we can ask about what the most beneficial things they anticipate (i.e., benefits of accelerated discharge planning). Accordingly, if the participant appears closed to conversation, we can ask what the most difficult things they anticipate (i.e., weaknesses of accelerated discharge).

To begin, I want you to envision the ideal ICU discharge. What does the best discharge from ICU to eventually going home look like to you?
[PROBES:

Why is this ideal for you?]

I would now like to address the first area of interest: your perspective on accelerated discharge planning.
As a reminder, when I say accelerated discharge planning, I mean when doctors and nurses work with the patient and family to plan for when the patient leaves the ICU. This accelerated discharge planning will begin when a patient is admitted to an ICU. This is a new idea because usually planning for discharge happens when a patient is ready to leave the ICU. Patients can be sent directly home or to a less intense unit in the hospital. Where they are sent depends on the health of the patient. Can you tell me about your thoughts around accelerated discharge planning?
[PROBES:
          What did you think accelerated discharge planning was prior to hearing the definition provided?
          How do you feel about the practice of accelerated discharge planning after hearing it's definition?
                    Open: What do you see as benefits of accelerated discharge planning?
                    Closed: What do you see as weaknesses of accelerated discharge planning?
          How does your experience shape your perspective?]

What would make you comfortable in being involved with accelerated discharge planning? Why?
[PROBES:
          What would have helped you feel supported during and after ICU discharge?]

What concerns you about accelerated discharge planning? Why?
[PROBES:
          What part(s) of accelerated discharge worries you?
          How do you think this differs from the current discharge practice?]

6. Elements to include in accelerated discharge plans

Now I would like to focus on the second area of interest: beneficial things to include in accelerated discharge plans. This can be anything that you would find supportive during the time before and during transitions in care. The hospital staff would work with you and your loved one to make an accelerated discharge plan that is specific to the patient's needs.

Please tell me what you think would be helpful to include in a discharge plan?
[PROBES:

Would educational and instructional considerations would be helpful? An example of an educational element is family participation in ICU care rounds so that you feel confident once the transition in care occurs. What types of instructional information?

Would wellness and supportive considerations would be helpful? An example of a wellness/supportive aspect could be online peer support groups to improve transitions in care or physically supportive considerations like a walking aid. What types of wellness things?

Would practical and hands-on considerations would be helpful? An example of a practical/experiential element could be nurses showing the family member how to assess your loved one for delirium so that you are confident doing this on your own once transitioned out of ICU. What types of practical experience?

What other elements would be helpful to include? Why?]

<u>What needs to be done before you leave the hospital so that you feel prepared and safe when you get home?</u>
[PROBES:
    And what else should be done before you leave hospital?]

<u>What needs to be done after you get home so that you feel prepared and safe to stay at home?</u>
[PROBES:
    And what else should be done after you get home?]

7. *Facilitators and barriers to accelerated discharge planning*

<u>Now on to our final area of interest: helpers and preventers to accelerated discharge planning. A helper is something that will make accelerated discharge easier. A preventer is something that will make accelerated discharge planning difficult. Please think about your experience. What would make accelerated discharge planning easier?</u>
[PROBES:
    What are individual considerations that would make accelerated discharge planning easier? An individual consideration is something about yourself (or others) that would help accelerated discharge planning.
        Ex: This could be your knowledge of your loved one and ability to notice slight changes in their behaviours.
    What are structural considerations that would make accelerated discharge easier? A structural consideration is something about the ICU or healthcare system that would help accelerated discharge.

Ex: This could be the desire of ICU staff to partner with patients and their family.
What are resources that would make accelerated discharge easier? A resource is something that is available to use that would help accelerated discharge.
Ex: This could be access to 811 health link nurses from home that you could use if any questions occurred.
What are other things would make accelerated discharge easier?]

Please think about your experience. What would make accelerated discharge planning difficult?
[PROBES:
What are individual considerations that would make accelerated discharge planning difficult? An individual consideration is something about yourself (or others) that would make accelerated discharge difficult.
Ex: This could be patients that do not have family that are able to take on the role of caretaker during their transition out of ICU.
What are structural considerations that would make accelerated discharge planning difficult? A structural consideration is something about the ICU or healthcare system that would make accelerated discharge difficult.
Ex: This could poor communication between ICU and the transfer destination.
What are resource limitations that would make accelerated discharge planning difficult? A resource limitation is something that we don't have enough of.
Ex: This could be not enough time to give you practical, hands on experience in ICU prior to discharge.
What are other considerations that would make accelerated discharge planning difficult?]

8. Open-ended comments or questions

We want to end the interview on a substantive note. To do this, we will return to short and easy questions

Do you have any questions for me about this interview or the study?

Is there anything you would like to add in light of what we have been talking about?

Is there anything you thought I would ask but did not, or anything else that you think is important for us to consider?

Do you consent to be contacted for an invitation to participate in an online survey?

Thank you for your participation in this interview. On behalf of the entire Study Team, we appreciate that you took the time to talk to us. We will email a gift card to you as a thank you.

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CHAPTER 3: DISCUSSION

3.1 Summary of Main Findings

The work presented in this thesis explores patient and family perspectives on accelerated discharge planning from ICU, patient- and family-centered supportive elements to potentially include in accelerated discharge plans, and anticipated facilitators and barriers to accelerated discharge planning. The study presented in Chapter Two is the qualitative first phase of a sequential exploratory mixed methods project examining patient and family perspectives on accelerated discharge planning, ranking priorities for accelerated discharge planning from ICU (**Chapter 2, Figure 1**). The study employed a descriptive qualitative approach leveraging semi-structured interviews with seven participants (n=2 patients and n=5 family) to explore their perspectives on accelerated discharge planning. The interviews were transcribed and analyzed per reflexive thematic analysis using an inductive approach with an experiential qualitative framework.(51)

Five themes related to patient and family perspectives on accelerated discharge planning in the critically ill were identified in the data: (1) Discharge planning process and stakeholder goal alignment; (2) Patient and family support needs in accelerated discharge planning; (3) Scope of support across care settings; (4) Individuality of dyads; and (5) Facilitators and barriers to accelerated discharge planning.

The findings in this thesis suggest that patients and families are receptive to accelerated discharge planning because accelerated discharge planning may provide opportunities for patients and family that are not present in current models of discharge; that is, the clinician-dyad partnership requirement of accelerated discharge planning is aligned with patient and family wishes for increased participation in care. Accelerated

discharge models elicit increased dyad-clinician communication and collaboration opportunities in planning decisions and care stewardship to facilitate greater continuity of care across settings.

Pending appropriate and accessible supports are provided to the patient and family dyad, there will likely be dyad buy-in regarding the practice of accelerated discharge planning from ICU. The type of supports required for patients and family include informational, psychological, and logistical. However, as the nature of patient and family roles shift according to care setting (i.e., in ICU, family as collaborator and advocate versus at home, family as primary caregiver), the form of the support may also differ across the various settings (i.e., in ICU, "big picture" informational resources to facilitate diagnosis and care trajectory understanding versus at home, curated contacts/information to support family in caregiver role). Thus, it is important to consider the suitability of the form of informational, psychological, and logistical supports offered in accelerated discharge planning to patients and family in relation to the care setting the supports are to be used in.

When creating an accelerated discharge plan, individualized considerations around dyad characteristics is paramount in helping to support the plan be both suitable to the patient's and family's goals and feasible for them to participate in. Accelerated discharge plans should use direct, clear language appropriate for the unique specifications of the dyad (i.e., comprehensibility considerations such as plans being offered in patient's and family's preferred language and education level). Further, curated and accessible support resources should be included in accelerated discharge plans to help facilitate successful transitions to the community. Exploring the possibility

of leveraging a designated "accelerated discharge planning manager" or liaison may alleviate practice barriers (i.e., staffing [in]availability) within ICUs and help facilitate successful accelerated discharge planning practices.

3.2 Findings in Relation to Existing Literature

Accelerated discharge is an innovative adult ICU care model that uses earlier initiation of discharge planning and leverages effective communication between clinicians and partnerships with patients and family. While this model of discharge is relatively new, and little is known about patient and family perspectives on accelerated discharge planning from ICU, patient and family perspectives of transitions in care have been examined.(54–56,58) Research has identified that patients and families perceive challenges while in ICU and before, during, and after transitions in care from ICU. Bailey and colleagues used the validated State-Trait Anxiety Inventory (64) and found that while patients are in ICU, family members have significantly higher anxiety compared to working adults (p<0.0002) and that not being aware of the transfer plan is one factor that can contribute to the anxiety of the family.(65) Similarly, op' t Hoog and colleagues found that at transitions in care from ICU, family of patients perceived that discharge from ICU was unexpected and cited feeling worried regarding the continuity of care due to the abrupt nature of the transition in care.(54) Our study found that initiating planning earlier may mitigate these reported challenges (54–59,66–68) experienced by family by quelling patient and family worries, fostering hope for the future, and enabling cognitive and logistic preparation for transition in care.

The potential for accelerated discharge planning to address current patient and family challenges in ICU and at transitions in care may be one contributor to the positive

perception of the practice by this stakeholder group. Beyond the potential to *address current challenges* experienced by patient and family while in ICU and at discharge, patients and family may be receptive to accelerated discharge planning because of the potential to offer patient and family the *opportunities* that these stakeholders have perceived to be lacking in current discharge practices. The Clinical Practice Guidelines for Support of the Family in the Patient-Centered Intensive Care Unit outlined how patient and family have expressed the desire for a larger role in healthcare decision making but often feel uninformed and excluded in care collaboration while in ICU.(69) Häggström and colleagues conducted a study assessing the perception of family on the quality of care that their loved one received during the transition process from ICU, and reported that 61% of family perceived their participation in the transfer process from ICU as inadequate.(56) Similarly, op 't Hoog and colleagues found that family wanted to be more involved in the discharge planning to step-down-units from ICU and felt disappointed in the level of their involvement in care by clinicians.(54) Forsberg and colleagues found that critically ill patients desired transfers out of ICU to be better planned and to involve them to facilitate feelings of control during the transfer process.(55) Rosgen and colleagues found that patients and family believed that transition in care discharge plans should facilitate more collaboration between patients and family and ICU clinicians.(60) Taken together, these studies suggest that patients and families want more involvement in discharge planning from ICU and greater care collaboration opportunities.(54–56,60,69) Our study suggests patients and families are receptive to accelerated discharge planning because it elicits increased dyad-clinician communication and collaboration on discharge planning from ICU, which are

opportunities that may be missed in other less collaborative, less communicative ICU

discharge models.

While no literature exists on patient and family support needs in accelerated

discharge plans from ICU specifically, recommendations put forth by Purdy and

colleagues to assist discharge planning from neonatal ICU suggest that emotional,

educational, and pre- and post-discharge resource coordination support are important

considerations in discharge planning.(47) Further, Purdy and colleagues suggest that

specific emphasis on follow up care for infants discharged earlier from neonatal ICU are

important considerations in discharge plans.(47) Our study in adults similarly found that

psychological, informational, and logistical supports are important considerations in

accelerated discharge plans and that follow up supports are an important provision in

the accelerated discharge planning process. Further, consistent with our finding that the

nature and timing of support needs for patients and family in accelerated discharge

planning varies across care settings, Purdy and colleagues noted that the form of each

support type provided to parents of premature infants varied to ensure suitability to the

specific care setting.(47)

The precedents set by Purdy and colleagues in utilizing general discharge

support recommendations with additional special considerations for the earlier

discharge population may be a suitable notion applicable to the adult population.(47)

Along this logic, looking more broadly at adult ICU transitions in care literature may be

warranted to help garner further information on patient- and family-specific

considerations in accelerated discharge planning. The need for informational supports

has been found to be a patient and family need in ICU (57,66,67) and to support

transitions from ICU across care settings.(55,56,58,59) In ICU, Khalaila and colleagues

found that unmet informational needs of family were associated with decreased

satisfaction of care and may have added to the challenges experienced by family in

ICU.(67) Similarly, Schwarzkopf and colleagues found in a prospective cohort study on

family satisfaction in ICU that families were dissatisfied with the clarity and

completeness of information (e.g., doctors jargon).(66) Forsberg and colleagues found

that patients wanted information about anticipated ICU stay duration and transfer plans

and appreciated being informed despite knowing that plans could change.(55) Our

study found that patients and family similarly desired information on anticipated ICU

stay duration and care trajectory suggesting that "ICU roadmaps" may be a useful

informational support for patients and family participating in accelerated discharge

planning. At ICU discharge, Häggström and colleagues found that family desired more

information to be available throughout the transfer process and cited information needs

as important to family.(56) After transfer into a less acute care setting, Häggström and

colleagues found that 53% of family members reported perceptions of inadequate

informational support after ICU.(56) Further, the concept of shared decision making,

that is central to accelerated discharge planning, relies on patient and family

empowerment.(69) Like our finding that informational supports are needed in

accelerated discharge planning to facilitate families to be self-efficacious caregivers

through care settings, Herling and colleagues suggested that information is a key factor

in bolstering patient and family empowerment in and beyond ICU.(59)

The traumatic nature of an ICU experience may contribute to the increased risk

of patients developing post-intensive care syndrome (PICS) and/or family developing

PICS-Family which involve physical, cognitive, and mental health impairments.(70)

Consequently, the need for psychological supports for patients and family while in ICU

is well documented. (47,56,67,69,71–73) At ICU discharge, Häggström and colleagues

found that reassurance was important for family in ICU discharge plans, which is

consistent with our finding of validation needs within the theme of psychological

supports in discharge plans.(56) Taken together, these findings indicate the importance

of both informational and psychological support resources for patients and families in

accelerated discharge plans.

The 2001 paper, Crossing the Quality Chasm, strongly recommended that

healthcare delivery systems shift to a more patient-centered focus with decision making

tailored to patients' preferences and goals.(1) In line with this health systems initiative,

strategies for individualizing discharge plans have been proposed to support improved

patient outcomes at transitions in care.(60) Patient-oriented discharge summaries

(PODS) are one such innovation to bolster a more patient-centered process, with the

discharge summary being co-designed with and individualized to the patient and

family.(61) In addition to the push for more patient-oriented discharge summaries,

Rosgen and colleagues found that adaptability of discharge tools to patient and family

were an important concern of stakeholders.(60) Specifically, transition in care bundles

(packages of tools used to support ICU discharge through the various phases of the

discharge process) should include adaptable tools so that the overall bundle can be

tailored to the patient and family's unique characteristics (i.e., patient diagnosis, primary

language), consequent needs, and location (i.e., adaptable to geographic location of

patient).(60) Similarly, in our study, patients and family suggested accelerated

discharge plans be collaboratively designed with the individual characteristics of the patient and family in mind to generate plans that are comprehensible (i.e., offered in dyad's language and education level), feasible for patient and family to successfully follow (i.e., family participation aligned with their capacity to be involved, relevant supports provided), and aligned with their goals.

The concept of PODS, as with the findings of Rosgen and colleagues, may be relevant to consider when crafting accelerated discharge plans due to the potential degree of transferability among traditional transition in care planning models and niche ICU discharge planning models (i.e., accelerated discharge planning).(60,61) For example, Rosgen and colleagues found that transition in care bundle supports that used video-based tools were not recommended due to inability to personalize content to the patient and family dyad and tools that used clear, positive lay language were better ranked.(60) These findings provide important stakeholder-informed considerations that may help to inform the eventual development of accelerated discharge plans.

While no other work has directly assessed patient and family perceptions on the facilitators and barriers of accelerated discharge planning, there has been patient and family evaluations on the facilitators and barriers to high-quality transitions in care to ward.(2,8) In a multicenter qualitative study evaluating patient, family, and provider experiences with transfer from ICU to hospital ward, de Grood and colleagues found that resource availability, in terms of both staff availability and material resources, were perceived to be barriers to high-quality discharge to ward by patients and family.(8) In our study, patients and family identified consistent staffing availability issues as a structural barrier to accelerated discharge planning and ideated around the potential of

leveraging a designated "accelerated discharge planning manager" or liaison to alleviate

structural barriers within ICUs. Chaboyer and colleagues found that the use of a liaison

nurse role in adult ICU had a statistically significant (p<0.001) impact on reducing

delays to discharge.(74) A systematic review by Tabanejad and colleagues reported

that use of nurse liaison roles in both adult and pediatric ICUs were beneficial in

facilitating greater continuity of care after discharge from ICU.(75) Therefore, while use

of a discharge manager role may require a financial outlay, there may be substantial

returns on investment through reductions in ICU discharge delays and hospital

readmittance post-discharge. Thus, the creation of a designated discharge planning

manager role, or augmentation of an existing role to include discharge managing duties,

may be beneficial in overcoming resource availability limitations, managing budget

constraints, and supporting the ICU's ability to engage with patients and family in

accelerated discharge planning.

3.3 Clinical and Public Health Implications

One of the main responsibilities of the Canadian healthcare system is to

contribute to health system improvements by providing high-quality care while utilizing

limited resources in an efficient, sustainable, and effective manner.(76) To support this,

funding is provided to healthcare research entities to direct research efforts to high-need

areas within healthcare wherein findings can be used to inform high-quality, resource-

efficient care practice.(76) Such healthcare research entities include Alberta Health

SCN and Critical Care SCN.(28) Evidence-informed healthcare research typically

targets at least one of three levels of prevention within public health (77): (1) primary

prevention which is the prevention of the incidence of a disease, (2) secondary

prevention which involves earlier detection and management of a disease, and (3) tertiary prevention which involves efforts to minimize the impact and burden of ongoing disease.(78) In the context of clinical and public health implications, the findings from this thesis are focused mainly on tertiary prevention, as the overarching aim is to support efficient, sustainable, and safe discharge of former critically ill patients out of ICU and hospital settings back into the community for continued recovery from illness.

Transitions in care from ICU were identified by our group, through partnership with the Critical Care SCN, as a significant quality improvement opportunity and essential priority for evidence-informed critical care research in Alberta (29,30) to reduce inefficiencies observed in current practice (1,8) and bolster readiness to meet forecasted capacity demands.(11,13,20) Thus, there is a pressing need for clinical practice to explore alternative, sustainable long-term solutions that employ streamlined ICU care with subsequent, optimized discharge planning and discharge. This thesis provides empirical evidence that patients and family, who are critical stakeholders in ICU discharge, are receptive to alternative models of discharge, such as accelerated discharge, that bolster patient and family engagement in planning and care. Consequently, accelerated discharge may be a promising avenue for more efficient discharge practices in the future. However, the findings from this study are part of the preliminary stages of a program of work exploring accelerated discharge and more research is warranted to provide evidence-informed discharge model policy changes. Nonetheless, in the interim, current transition in care models should seek to incorporate opportunities that are patient- and family-oriented in ICU and before, at, and after

transitions in care to support optimized discharge practices within the confines of current discharge planning models.(79)

In all discharge models, discharge planning from ICU is required prior to the transition in care and involves the process of identifying and preparing the patient and family (as family members are important in the care of critically ill patients in ICU, hospital, and once at home [29,30]) for the patient's anticipated care needs after they leave the ICU and hospital.(82) However, in current discharge models, the level of discharge planning and input from patients and family on developing discharge plans may be inadequate or absent, given the magnitude of post-ICU impairment (e.g., PICS or PICS-Family).(70,83) Further, the literature suggests that patients and family are dissatisfied with their current level of involvement in discharge planning from adult ICU.(54,55) Thus, in ICU, efforts to increase communication and engagement of patients and family in care and discharge planning should be made. It is important that the necessary informational supports are in place to allow patients and family to understand their role in care and discharge planning so that they are empowered to be contributors to the care team.(54) Clinical practice could consider the use of "ICU roadmaps" for patients and family once in ICU to help foster their understanding of what is happening, of the anticipated care trajectory, and to contextualize their role in the care team and in transitions in care. When planning for discharge and developing discharge plans, it is important to consider collaboratively designing patient- and family-oriented discharge plans with the individual characteristics of the patient and family in mind to generate plans that are understandable (i.e., clear, direct, offered in dyad's language and education level), feasible for patient and family to successfully follow (i.e.,

appropriate informational and psychological supports provided), and compatible with

their preferences. This can be incorporated into practice by encouraging the use of

existing patient-oriented discharge summaries, such as PODS (61), to collaborate with

patients and families in crafting patient- and family-informed, individualized discharge

tools that support the patient and family throughout transitions in care. Creating patient-

oriented discharge plans are a time-intensive endeavor, thus, leveraging time-saving

technologies such as electronic tools to auto-populate certain areas of discharge plans,

should be explored. Li and colleagues reported that, as of 2015, among ICU providers

surveyed, only 28% used electronic discharge summary tools while 85% believed

electronic discharge summary tools could improve patient care.(84) Therefore, exploring

the intersection of dyad-clinician collaboration and automatic electronic population for

discharge summaries may be one way to balance the need for patient orientation and

efficiency, respectively. Care and support shouldn't stop once patients and family are

discharged into the community, yet patients and family cite perceptions of inadequate

support after discharge.(56) Our study found that patients and families require a broad

scope of care and desire supports to be in place once back in the community. Other

studies (34,47,60) have examined how transitions in care bundles can support

continuity of care in the community through use of healthcare practitioner follow ups and

community support groups. Thus, current discharge planning should seek to include

support provisions for patients and family once in the community to encourage better

continuity of care of current transition in care models.

3.4 Strengths

This study has several strengths. First, the semi-structured interview guide was developed per the five phase framework proposed by Kallio and colleagues to support rigorous data collection: (1) identifying the prerequisites for using semi-structured interviews; (2) retrieving and using previous knowledge; (3) formulating the preliminary semi-structured interview guide; (4) pilot testing the guide; and (5) presenting the complete semi-structured interview guide.(85) The preliminary interview guide was informed by narratives reported in previous research on patient-oriented ICU discharge planning.(8,54,55) We pilot tested the interview guide in a "field test" (85) format (i.e., technique where preliminary interview guide is tested with a potential study participant) to simulate a real interview situation and elicit intelligibility. In addition to abiding by the framework for semi-structured interview development, we bolstered rigorous data collection by using a multi-disciplinary team of ICU patient and family partners, researchers, and a critical care physician to develop and refine the interview guide to incorporate multiple stakeholder views. Second, semi-structured interviews were conducted individually with patients, family, or patient-family dyads which allowed for the time and psychological safety needed for participants to delve into how their experiences in ICU informed their perspectives on accelerated discharge planning from ICU. Third, we used reflexive thematic analysis with an inductive data orientation to support experience-driven theme development which was warranted due to lack of pre-existing knowledge regarding patient and family perspectives on accelerated discharge planning from adult ICU.(51,86) Fourth, researchers practiced reflexivity to promote continual evaluations of personal, disciplinary, and participant assumptions to bring

awareness to biases, interrogate how biases may influence data collection and analysis and enhance the depth of analysis and discussion through situated, reflexive interpretation.(51) Reflexivity is an essential component in reflexive thematic analysis, and more broadly, in qualitative studies, due to the degree of subjectivity present. By practicing reflexivity, researcher subjectivity is valuable, rather than problematic, and aids the depth of research outputs.(51) Fifth, strategies to bolster the components of qualitative rigor were used and included supporting: i.) credibility (truth-value) through situated, reflexive interpretation, extensive depth of researcher engagement with the data and collaborative coding (the measures of analysis quality most appropriate for reflexive thematic analysis [51]), member-checking the interview guide for face validity and final themes, and peer debriefing, ii.) dependability (consistency/reliability) through extensive audit trails of study protocol and data analysis, iii.) transferability (extent to which findings can be applied to adjacent groups or processes) by connecting findings with accelerated discharge panning in the neonatal ICU literature and adult transition in care literature, and iv.) confirmability (transparency) through use of the COREQ reporting guidelines to make explicit how our study was conducted to enable repeatability.(51)

3.5 Limitations

This project has limitations to consider. First, due to the impacts of the COVID-19 pandemic, many potential participants were ineligible due to extended ICU stays and/or duration of mechanical ventilation received, which impacted recruitment. As such, we deviated from our intended purposeful sampling (for representation of gender, socioeconomic status, and ethnicity) in favour of convenience sampling which is known

to be a less rigorous sampling procedure. The change in sampling approach prohibited exploration of the association of sociocultural factors that may have impacted perspectives of accelerated discharge planning from ICU and perceptions of family capacity to be actively involved through transitions in care. Second, while themes were consistent across participants and there was considerable "information redundancy" (62), thematic saturation likely was not reached due to the limited sample size. While the findings from this study provide a baseline understanding of patient and family perspectives on accelerated discharge planning from ICU, a larger, more diverse sample would provide greater breadth of understanding of patient and family perspectives on accelerated discharge planning and more opportunity to ascertain if thematic saturation was reached. Third, assessment of generalizability should not be considered until we can ascertain if thematic saturation was successfully reached.

3.6 Directions for Future Research

The work presented in this thesis examining patient and family perspectives on accelerated discharge planning in the critically ill is the first phase of a sequential exploratory mixed-methods project which is the preliminary project nested in a larger Transitions in Care Team Grant (NPA, Fiest). The second phase of this research program should seek to rank patient and family support needs in accelerated discharge plans, as identified in this study, to distinguish the most important priorities for dyads and investigate specific support needs for individuals from various cultural, religious, and socio-economic backgrounds through use of a more diverse and representative sample.

Future studies should seek to understand the perspectives of other relevant stakeholders in accelerated discharge planning from ICU; this includes critical care clinicians, ICU administrators, and healthcare systems. Once relevant stakeholder perspectives, priorities, and concerns have been garnered, research should work to build accelerated discharge planning protocols that incorporate stakeholder-informed considerations as well as the tenants of ideal discharge planning practices (79) in order to develop *optimal, broadly informed* accelerated discharge planning protocols. Once accelerated discharge planning protocols are developed, effectiveness and implementation trials should be conducted to evaluate said protocols in real-world conditions and the fidelity of such a practice which can in turn, inform clinical practice guidelines on discharge planning protocols from Canadian ICUs.

3.7 Conclusions

The work presented in this thesis found that former critically ill patients and family of former critically ill patients positively view accelerated discharge planning, as the opportunities provided in this transition in care model are aligned with patient and family goals of care (i.e., earlier initiation of discharge planning, dyad input in discharge planning, increased dyad-clinician communication, family collaboration in care). Individualized, realistic accelerated discharge plans that provide informational, psychological, and logistical supports to patients and family throughout all care settings may help facilitate successful transitions in care. While this is a preliminary first step in investigating the feasibility of accelerated discharge planning, it is a promising stride that will help catalyze other research towards more sustainable, efficient, and patient- and family-oriented transition in care practices in Canadian ICUs.

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