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A NARRATIVE STUDY OF ALTERNATE LEVEL OF CARE

A NARRATIVE STUDY OF THE OLDER PATIENT AND FAMILY CAREGIVER EXPERIENCE OF ALTERNATE LEVEL OF CARE

By

Greg Cressman, B.Sc., B.Sc.N.

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Master of Science (Nursing)

McMaster University

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ABSTRACT

Alternate Level of Care, or ALC, is a designation assigned to a patient during an acute care hospital stay when that patient is occupying a bed but no longer requires that intensity of service. A high proportion of beds occupied by patients requiring ALC results in problems in the healthcare system related to patient flow, access, and efficiency. The purpose of this study was to better understand the experience of older patients and family caregivers while the patient is designated as requiring ALC. This study employed the Three-Dimensional Narrative Inquiry Space method of Clandinin and Connelly (2000) to examine the experiences of five patients and four family caregivers. The primary data source for this study was a series of semi-structured interviews with individual participants over time while they were in the midst of the experience of ALC. Data analysis involved a twofold process of restorying all interview transcriptions for a given participant into a single story summarizing his or her experience, and analyzing the content across stories to identify common themes. The major finding of this study was that uncertainty was a significant part of the experience of ALC. This uncertainty was manifest in relation to self-concept, waiting for placement, not knowing about information, not being included in planning, lack of mobility, and lack of meaningful activity. The study findings have implications for strategies to manage uncertainty in the areas of practice, policy, education, and research in order to improve the experience of older patients and their family caregivers.

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TABLE OF CONTENTS

ABSTRACT…..……..……..……iii
ACKNOWLEDGEMENTS…..……..……iv
TABLE OF CONTENTS…..……..……..……v
LIST OF TABLES…..……..……..……...viii
LIST OF APPENDICES…..……..……..ix
LIST OF ABBREVIATIONS…..……..……..…....x

CHAPTER 1- INTRODUCTION…..……1

The Problem of Alternate Level of Care (ALC) …..……..1
Defining ALC…..……..……..……1
ALC as a Symptom of Health System Problems…..……..…...2
The Need for a Patient Perspective on the Problem of ALC…..……3
Beginning in the Midst of Stories…..……..……4
My Experiences Working in Home Care…..……..……4
My Experiences in Hospital…..……..……5
The Importance of Patient Voice…..……..……6
The Research Question…..……..……..……..6
Organization of the Thesis……...7

CHAPTER 2 - LITERATURE REVIEW…..……..……...9

Introduction…..……..……..……...9
Literature Search Strategy…..……..……..……9
Older Adults and The Problem of ALC in Canada and Ontario……..……10
A Framework for Understanding Problems Related to ALC…..……..12
Responding to the Problem of ALC……..……..……..16
The Importance of Patient and Family Perspectives on ALC…..……..…..18

CHAPTER 3- METHODS…..……..……..……21

Narrative Methodology…..……..……..……...21
Assumptions Underlying the Narrative Approach of this Study……..……..21
The Three-Dimensional Narrative Inquiry Space Approach……..……...22
Setting…..……..……..……..23
Participants…..……..……..……..24
Recruitment and Sampling …..……..……..……25
Process Consent…..……..……..……...27
Data Collection…..……..……..……29
The Interviews…..……..……..……..29
Field notes…..……..……..……30
Data Analysis…..……..……..……...30

Strategies to Ensure Rigor…..……..……..……...33
Maintaining an Audit Trail…..……..……..…..33
Congruence Between Chosen Methods and a Narrative Approach……..……34
Participant Selection Criteria…..……..……34
Prolonged Engagement…..……..……..……35
Processes of Checking and Confirming…..……..……..35
Broadening the Feedback…..……..……..……36
Ethical Considerations…..……..……..……..37

CHAPTER 4 - FINDINGS: PARTICIPANT STORIES…….……..…….40

Overall Description of Study Participants…..……..……..…40
Stories of the Participants…..……..……..……40
The Story of Dan and Sarah: I Never Thought I'd End up my Life Like This…..……..……..….41
The Story of Teresa and Janice: Your Life is Passing You By, and You're Not Going Anywhere…..……..……..49
The Story of Bob and Alan: I Don't Have a Future……..……..……...57
The Story of Nancy and Barb: At My Age, What Is There to Hope For? …….66
The Story of Frank: I Just Take Things as They Come and Roll With the Punches. …..……..……74

CHAPTER 5: FINDINGS: THEMES ACROSS STORIES……..……..……78

Introduction…..……..……..……..78
I Don't Know…..……..……..……...80
I Don't Know… the Right Questions to Ask: Problems With Communication……..80
I Don't Know… About Hospital Processes……..……..……81
I Don't Know… About the Placement Process……..……..……..84
I Don't Know… About Medical Assessment, Diagnosis, and Prognosis……..….88
Waiting…..……..……..……90
Waiting to be More Mobile…..……..……..…..90
Longing for Meaningful Activity…..……..……92
Waiting for Care…..……..……..……..95
Waiting for Placement…..……..……..……..96
Waiting for Couple Reunification…..……..……..…99
I Never Thought I'd End Up My Life Like This……..……..……..102
The Past: "I Was on the Go All the Time"…….....……102
The Present: "I Never Thought I'd End Up My Life Like This" ……..……..106
The Future: "At My Age, What is There to Hope For?" ……..……..…109

CHAPTER 6: DISCUSSION…..……..……..…..113

Discussion of Findings…..……..……..……..113
Uncertainty and the Experience of ALC…..……..……..114
Uncertain Self-Concept…..……..……..……..114
Uncertainty and Interactions in the Hospital Environment……..……...118
Not knowing: Lack of information. …..……..……..118
Not knowing: Inadequate participation. …..……..……..120
Lack of mobility. …..……..……..……122
Lack of meaningful activity. …..……..……123
Uncertainty of Time and Place: Waiting for Placement……..……..…..125
Implications for Practice, Policy, Education, and Research……..……..……127
Practice…..……..……..……..127
Policy…..……..……..……..…132
Education…..……..……..……...137
Research…..……..……..……139
Limitations of this Study…..……..……..……...141
Conclusion…..……..……..……..143

REFERENCES…..……..……..……146

LIST OF TABLES

Table 1…….79

LIST OF APPENDICES

Appendix A: Patient Screening Documents……161

Appendix B: Patient Recruitment Script…..……...…166

Appendix C: Family Caregiver Recruitment Script…….…...167

Appendix D: Patient Information Letter…….….168

Appendix E: Telephone Script for Family Caregiver Contact - A……..……170

Appendix F: Telephone Script for Family Caregiver Contact - B……..…171

Appendix G: Patient Consent Form……172

Appendix H: Patient Biographical Information……..173

Appendix I: Family Caregiver Information Letter…….....…174

Appendix J: Family Caregiver Consent Form…….....…176

Appendix K: Family Caregiver Biographical Information: ……...…177

Appendix L: Patient Interview Guide…….....…178

Appendix M: Family Caregiver Interview Guide…….……..181

Appendix N: Five Stories: Patient and Family Caregiver Participants…….….184

LIST OF ABBREVIATIONS

CCAC	Community Care Access Centre
LHIN	Local Health Integration Network
LTCH	Long-Term Care Home
MOHLTC	Ministry of Health and Long-Term Care

CHAPTER 1: INTRODUCTION

The Problem of Alternate Level of Care (ALC)

Defining ALC

Alternate Level of Care, or ALC, is a designation assigned to a patient during a hospital stay. The Ontario Ministry of Health and Long-Term Care (MOHLTC) has adopted the following definition of ALC:

> When a patient is occupying a bed in a hospital and does not require the intensity of resources/services provided in this care setting (Acute, Complex Continuing Care, Mental Health or Rehabilitation), the patient must be designated Alternate Level of Care (ALC) at that time by the physician or her/his delegate. The ALC wait period starts at the time of designation and ends at the time of discharge/transfer to a discharge destination (or when the patient's needs or condition changes and the designation of ALC no longer applies) (Cancer Care Ontario, 2009).

The term ALC is used across Canada (Canadian Institute for Health Information [CIHI], 2009). In the United Kingdom (UK) the term *delayed discharge* or *delayed hospital discharge* is predominantly used to denote the same phenomenon (Glasby, Littlechild, & Pryce, 2006). The term *bed blocker* has also been used to denote ALC but recently appears only infrequently in the literature as it is now generally understood to be a pejorative term that inaccurately suggests that the cause of the problem is the patient occupying the bed (Scott, 2000).

In this thesis, I will use the phrase 'patients are designated *as requiring* ALC' rather than the above wording of 'patients are designated ALC.' This phrasing is intended to better respect the personhood of patients by lessening the effect of a label in the same way that one would prefer to speak of a person as having diabetes rather than

calling a person a *diabetic*. As well, this phrasing is intended to ally the reader with the patient in examining the problem of needing a more appropriate place of care.

ALC as a Symptom of Health System Problems

A high proportion of beds occupied by patients requiring ALC causes problems in the health care system related to access and efficiency (Ontario Health Quality Council [OHQC], 2010). Access is threatened because patient flow through the hospital is impeded. This occurs because patients designated as requiring ALC are not able to leave the hospital for a more appropriate place of care and therefore continue to occupy a bed which could be available for a new patient. This results in increased wait times in the Emergency Department (ED) and for elective surgery (OHQC; Wait Time Alliance, 2011). As well, the efficiency of the system is reduced because patients are being cared for in a more expensive place than necessary (OHQC).

ALC is best understood as a symptom of complex and multiple problems originating in the health care system itself (OHQC, 2010; Ontario Expert Panel on Alternate Level of Care, 2006). In other words, the primary causes of ALC originate in the existing systems of patient care. In particular, the growing problem of ALC appears to reveal problems in the organization of health and social services designed to meet the needs of older adults. As the Canadian Special Senate Committee on Aging reported in 2009, “A health system designed to deal with episodic illness is ill prepared to deal with the rise in chronic illness associated with an aging population” (p. 33).

Given continuing increases in the life expectancy and remaining years of expected life at age 65, the proportion of Canadians aged 65 years or older is expected to

almost double over the next 40 years from the current level of 14% to more than one quarter (27%) of the total population (Butler-Jones, 2010). Given the trend toward an increased proportion of older adults in Canada in the coming decades, there is concern about the ability of existing systems of care to meet the needs of older adults in the future (Alzheimer Society of Canada, 2010; Canada Special Senate Committee on Aging, 2009). In Ontario, popular media (for example, Howlett, 2011) and public documents (for example, Bronskill et al., 2010) make a direct linkage between the growing problem of ALC and the future needs of an aging population.

The Need for a Patient Perspective on the Problem of ALC

Recent national and regional news media have carried stories describing the phenomenon of ALC and its impact on the health care system, patients and families (Frketich, 2009; Howlett, 2010). The tone of the media coverage is often negative and generally examines the problem from a system perspective rather than that of a patient, as conveyed in the following newspaper quote: "Anywhere from 15 to 25 per cent of area hospital beds *are blocked by* [italics added] seniors waiting for long-term care, homecare or other services" (Frketich, 2010). Unfortunately, this system perspective leaves the impression that older adults are the cause of the problem and discounts their unique personal stories and experiences within the system of care.

The literature examined for the current study has revealed that the patient and family perspective is poorly reflected in research related to ALC. A recent review of the literature on delayed discharge in the UK makes particular note of this lack (Glasby et al.,

2006). Clearly, the perspective of the patient is very important, and may in fact lead to more effective solutions to problems related to the healthcare system including ALC.

Beginning in the Midst of Stories

Clandinin and Connelly (2000) believe that researchers come to the process of conducting a study in the midst of living their own story while engaging with participants in the midst of living theirs, and that these two sets of stories nest into and shape one another through the process of research. With that understanding in mind, I will relate some of the stories of my own life that have shaped, and continue to shape, the research story that has emerged in the present study.

My Experiences Working in Home Care

I began my nursing career as a Visiting Nurse providing palliative care to patients in their homes. Many of the patients I cared for were older adults. My role involved careful listening to the accounts patients and families gave of their experiences with illness and the ways they were managing the challenges of day-to-day life, and addressing those challenges in order to help them remain in their home as long as possible. At times, given changing circumstances or changing wishes on the part of the patient, I assisted them to change their place of care, either to hospital to address acute changes in their illness, or to another place of care with different resources better able to meet their needs. Such transitions were always challenging for patients, and I learned how difficult it was as a nurse to plan and exchange information across different sectors of the healthcare system on behalf of patients.

My Experiences in Hospital

In 2008, I began working as part of a multidisciplinary team providing Palliative Care in a hospital setting. Though much of my clinical experience with patients and families transferred easily, I soon discovered that I had much to learn about processes of care within the hospital in order to be helpful to patients and families. In my career as a Visiting Nurse, my point of view regarding hospitals was largely that of an outsider, uninformed by direct personal experience. My work included experiences at the interface between these two very different parts of the healthcare system, an interface that was often quite challenging for patients and families to navigate, and challenging for me to help them. For example, when admitting patients into my care in the home following a hospital discharge, I often received very little information or guidance from the hospital about the history of that hospitalization, and the treatments and medications required to continue their care. My present work has allowed me to experience that interface from a different perspective, that of an insider to the hospital. However, problems with the interface are no easier from this perspective as I strive to coordinate and communicate with community based services about a safe and effective plan for discharge on behalf of patients in the midst of the complex and time pressured environment of the hospital.

At the same time that I started my new job, I returned to school to study in a Master of Nursing program. As part of my education, I had a six month clinical placement in hospital with a Geriatric Assessment Team. As a result of this placement, I learned about specialized care provided for older patients and their families. Through this educational opportunity and with my ongoing work, I became much more aware of the

challenges faced by hospitalized older patients, including some perspectives on the patient experience of being designated as requiring ALC. For example, I noticed a change in the level of service resourcing that occurred once the designation had been applied: few visits from doctors, less time allotted for therapies, and a lower ratio of nurses to patients. I also noticed that patients seemed caught in a kind of limbo, waiting for placement sometimes for weeks on end, and that they often felt lonely and sad.

The Importance of Patient Voice

A memorable part of my visiting nurse experience was the radical reshaping of the system of Home Care in Ontario that occurred in the mid 1990s (Aronson, 2002; Aronson, 2006). During this time, I learned that many older patients affected by the service cuts were reticent to speak publicly about their concerns for fear there would be repercussions for their care. When some did choose to speak, the stories were powerful, and displayed in a unique and moving way the effects of the changes that were occurring. In the midst of this time, I became aware of research that had been conducted to explore and document the patient experience of these changes to Home Care (Aronson, 2002; Aronson, 2006). At the time, I found it meaningful that a research study could help give voice to older patients who were in a vulnerable position.

The Research Question

I decided to study ALC because of my experiences in community and hospital with older adults, my recognition of the problems associated with ALC, and the need for patient voice to be heard on a significant problem related to patient care. With this

objective in mind, and supported by current literature on the topic I formulated the research question, and chose narrative as a method well suited to this purpose.

This study was designed to address the following research question: What are the experiences of hospitalized older patients and their family caregivers after the patient is designated as requiring ALC? The main purpose of this study was to better understand these experiences and to explore with participants their understanding of the term ALC, their information needs during this time, aspects of care that were positive or negative, feelings that were part of this experience, effects of this experience, and hopes, fears and worries about the future. The narrative method of Clandinin and Connelly (2000) was chosen as the design for this study and guided all decisions related to the methods. This approach was well suited to the purposes of this study because it emphasized personal and social interactions, the importance of place or a series of places, and the importance of time, including how present experience changes in the midst, and how those experiences are continuous (or not) with past and future experiences. Narrative research gives voice to participants by providing a research account that gives a story about the participant's experience.

Organization of the Thesis

In Chapter 2, I discuss a review of the liteature on ALC that extends the analytic overview provided in this introduction to more clearly define the phenomenon of ALC and explore possible causes and solutions to ALC, including the need for research on patient and family caregiver perspectives. In Chapter 3 I provide further background and

rationale for the narrative method chosen for this study, and describe the study methods including strategies to ensure rigour, and ethical considerations.

Chapter 4 provides a description of the nine study participants and presents five restoried narratives of the five patient/family dyads followed for the study. The first four stories interweave the narratives of the patient and their family caregiver to produce one account of their shared experiences, and the final story presents the patient story alone.

Chapter 5 presents the themes about the ALC experience identified across participant narratives. The overall theme of uncertainty was composed of three main themes: (a) I don't know; (b) waiting; and (c) I never thought I'd end up my life like this. Each theme is described in detail, with relevant sub-themes and supporting quotations.

Chapter 6 presents a discussion about the thematic analysis of the patient stories. Here I review the main findings of this analysis and link these findings with the existing research literature. I then discuss the implications of these findings for practice, policy, education, and research.

CHAPTER 2: LITERATURE REVIEW

Introduction

This literature review will deepen the analytic overview of ALC that was outlined in the first chapter. This review will begin with a description of the characteristics of ALC across Canada and within Ontario with a particular focus on the problem of ALC as it impacts older adults. The framework of Glasby will then be used to guide an analysis of the literature with the goal of better understanding problems related to ALC and possible solutions to these problems. This review will conclude by examining the case in the literature for further research into the patient and family experience of ALC in order to improve those experiences and to better understand possible solutions to reducing the actual frequency of occurrence of ALC.

Literature Search Strategy

Government and organizational reports related to ALC were identified by searching the World Wide Web with Google using the term *alternate level of care*. This search identified a number of documents related to ALC in Ontario. The reference lists for these documents were reviewed to identify other relevant material including the key Canadian report on ALC by the Canadian Institute for Health Information (CIHI) (2009).

A literature search was also conducted in three databases to summarize the healthcare literature. The search terms used in each case were *alternate level of care, delayed discharge, long stay patients,* and *bed blockers.* The databases searched were Ovid Medline from 1950 to 2011 (week 33), CINAHL from 1981 to July 2011, and EMBASE from 1980 to 2011 (week 33). The reference lists from several key articles

were searched to identify other relevant research, and these same key articles were also forward cited in Web of Science to identify any recent articles which cited the index article. The majority of relevant studies originated in Canada and the UK although a few studies were reviewed from other countries.

Older Adults and the Problem of ALC in Canada and Ontario

Across Canada, there is rising concern that the problem of ALC is having an increasingly negative impact on an already taxed hospital system (Canadian Institute for Health Information [CIHI], 2009) causing problems of access and effiency in the larger healthcare system (OHQC, 2010). Between 2005 and 2008, the proportion of ALC hospital days across Canada rose from 10% to 14% of all hospital days (CIHI, 2009). The median ALC length of stay across Canada was 10 days in 2007-2008, while 20% of patients stayed in hospital more than a month under ALC designation, and 4% were ALC for more than 100 days

In Ontario, a recent planning document for the Ontario Ministry of Health and Long-Term Care (MOHLTC) reported that about 18% of acute care beds in Ontario's hospitals are occupied by patients who are designated as requiring ALC (Ontario Ministry of Health and Long-Term Care [MOHLTC], 2011a). A recent survey of hospitals by the Ontario Hospital Association (2011) confirmed this figure of 18%, and also found that the proportion of acute care beds occupied by ALC patients varied significantly between different regions of the province, ranging from 9% to 24% across

the 14 LHINs[1]. The LHIN in which the hospital in the current study is located had a rate of 19%. This variation suggests the importance of local factors (see Glasby et al., 2006) in influencing the magnitude of the ALC problem in Ontario.

The patient groups occupying higher proportions of ALC bed days across Canada are: (a) patients who are older adults (the median age for patients designated as requiring ALC is 80 years compared to 63 years for those who were not designated ALC); (b) patients with multiple illnesses i.e. at least one illness in addition to the illness that brought them to hospital in the first place; (c) patients with a diagnosis of dementia; and (d) patients who are recovering from a stroke (CIHI, 2009). As a result of the system problems described by the Special Senate Committee, older patients in hospital under the ALC designation often have few post-hospitalization options beside Long-Term Care Home (LTCH)[2] and therefore often have to wait some time until they can move to a more appropriate level of care.

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[1] Local Health Integration Networks (LHINs) are regional organizations appointed by the MOHLTC with a mandate to plan and integrate health care services across 14 geographic regions of Ontario.

[2] In Ontario, LTCH refers to facilities that provide care for people who are not able to live independently and require 24 hour nursing or personal care, support, and/or supervision (Bronskill et al., 2010). This includes LTCHs, charitable homes for the aged, and municipal homes for the aged. The LTCH admission process is centrally managed through regional waiting lists (Bronskill et al., 2010). Retirement Homes are privately owned rental accommodations for seniors who are able to manage and pay for their own care (Ontario MOHLTC, 2011b). Generally, retirement homes are designed for seniors who need minimal to moderate support with their daily living activities. These settings enable residents to live as independently as possible, while providing certain services and social activities.

In Ontario, the Institute for Clinical Evaluative Sciences reported that the proportion of all inpatient hospital days for adults aged 65 years or older represented by patients designated as requiring ALC was 23% in 2008/09 (Bronskill et al., 2010). This was 5% higher than the mean figure of 18% across all patient populations. For patients who were designated as requiring ALC and waiting for placement in LTCH, the median wait time for LTCH increased by 122% from 22 days in 2003/04 to 55 days in 2008/09. Finally, in all characteristics measured, the authors of the report note a great variability in the ALC data across the province. For example, for adults aged 75 to 84 years, the proportion of all inpatient days represented by ALC varied from 14% to 37% across the 14 LHINs in the province. Once again, this variability suggests that factors related to the local systems of care for older adults have a significant impact on the phenomenon of ALC.

A Framework for Understanding Problems Related to ALC

Glasby (2004) proposes an overarching framework which is helpful for better understanding and responding to problems associated with ALC. He suggests that the problems related to delayed discharge in the UK fall into three concentric and expanding circles or levels of concern: individual, organizational, and structural. The individual level refers to the way in which individual healthcare providers interact with patients and families, and addresses issues such as effective communication. The organizational level encompasses concerns about the effectiveness of care practices and policies within and between organizations. The structural level highlights the need for central (national or federal) government action to help address financial, legal and administrative obstacles to

collaboration between organizations, particularly the challenging structural divide that exists in the UK between health services and social services in terms of financing and regulation (Glasby, 2004).

The individual level in the Glasby (2004) framework is not intended to incorporate patient and family factors like patient demographics and personal choice. Rather, the individual level in this framework refers to individual healthcare providers and the nature of their interactions with patents and families. Much literature examined for the current study does report on patient and family factors associated with ALC. Although patient factors such as choice[3] do influence the phenomenon of ALC, and although such analysis is useful to identify the populations of patients that are impacted by ALC, such an approach runs the risk of distorting the analysis and wrongly implying

[3] Patient choice in Ontario includes decisions the patient makes about which facility they will move to after discharge from hospital. Although the level of care placement needed (LTCH versus Retirement Home) is largely determined by factors outside the control of the patient (for example, their functional ability), patients in Ontario are allowed to apply for up to three LTCH at any given time (Ontario MOHLTC, 2011c). While in hospital, patients who have been designated as requiring ALC while waiting for LTCH are required by provincial legislation to pay a daily fee known as the ALC co-payment. The maximum fee charged is the same as that for basic accommodation in LTCH. Variations on the timing and amount of this fee are charged in most provinces in Canada as one of several policies to "facilitate movement of ALC patients across the continuum of care" (Ontario Association of Community Care Access Centres, Ontario Association of Non-Profit Homes and Services for Seniors, Ontario Hospital Association, & Ontario Long-Term Care Association, 2006, p. 25).

that the major cause of the problem resides in factors related to patient characteristics. Victor, Healy, Thomas, and Seargeant (2000), for instance, suggest that patient and family characteristics account for only 20% of all factors which are associated with delayed discharge.

The individual level proposed by Glasby focuses on problems associated with communication between healthcare providers and patients, families, and other providers. Recent studies of the patient experience of ALC have all noted concerns about communication with their healthcare providers (Doleweerd & Berezny, 2009; Kydd, 2008; Swinkels & Mitchell, 2009). In particular, the study by Doleweerd and Berezny noted that patients and families reported that: information was inaccurate or unavailable; the system of access to LTCH placement was incomprehensible: there was a lack of preplanning for discharge; they received confusing financial messages; and there was insufficient help for the family. Glasby (2004) noted similar problems identified by patients and families in the UK.

At the organizational level, problems related to ALC are reflected in concerns about the effectiveness of care practices and policies within and between organizations. Glasby (2004) points out that many factors contributing to the delay of discharge can be found within the hospital itself including a shortage of allied health workers like occupational therapy. Factors such as problems with medication prescribing, waiting for test results, and waiting for assessment have all contributed to inappropriate delays in discharge (Houghton, Bowling, Jones, & Clarke 1996). Victor and colleagues (2000) examined the factors associated with delayed discharge of older people following a stay

on elder care wards at three acute care hospitals in England and found that the nature of the particular discharge assessment team staffing at each of the three study sites was independently associated with delay. In particular, the nurse coordinated team resulted in more delays than the other two sites which were coordinated by an occupational therapist in one case and a social worker in the other.

Difficulties in the relationship between organizations also contribute to the problem of ALC. For instance, through interviews and focus groups with key managers and practitioners involved in the planning, management and delivery of intermediate care services in the UK (for example, rapid response, Hospital at Home, supported discharge, and residential/day rehabilitation), Glasby, Martin, and Regen (2008) explored the relationship between those services and hospitals. Overall, the study identified a range of tensions which impeded their ability to address the problem of delayed discharge. As one of the participants said regarding this relationship,

> "I think our view is that you will only get a real interface if it's a working environment where there is some sort of working link between people in the community and people in hospital so that you can start to develop an understanding between clinicians of what is possible" (Glasby et al., p. 646)

Finally, the structural level highlights problems related to ALC that are rooted in the structure of the health and social care system itself. In the UK, Glasby (2004) speaks of the structural divide that exists between health services and social services, pointing out that health care is provided free by the National Health Service while social care is provided by local services which charge on a means tested basis. As well, he points out that a series of political, legal, professional, and administrative divisions create

significant barriers to effective collaboration between health and social care agencies. In other words, some of the organizational and individual problems described above interconnect with these fundamental structural concerns. In Canada, a similar lack of integration between health and social care also creates barriers to effective collaboration between these sectors (Béland et al., 2006; Butler-Jones, 2010; Special Senate Committee on Aging, 2009).

As well, the structural level includes consideration of gaps in the system of patient care which result in high rates of ALC bed days in hospital. Although their literature review is critical of the overall strength of the evidence related to delayed discharge in the UK, Glasby, Littlechild, and Price (2006) found that a significant gap in intermediate care services in the system of care for older adults contributed to delays. Taken together ,then, the individual, organizational, and structural levels described by Glasby provide a helpful framework for better understanding and responding to problems associated with ALC.

Responding to the Problem of ALC

Overall, Glasby and colleagues (2006) see organizational and structural level factors as the root cause of the delayed discharge phenomenon. Although they point out that evidence regarding possible solutions to reducing the occurrence of delayed discharges is quite limited at this time, they strongly suggest that solutions to the complex and multifaceted problem of delayed discharge must seek whole system approaches that address concerns at all levels of the Glasby (2004) framework. In Canada, for instance, a randomized controlled trial by Beland and colleagues (2006)

found that there was a 50% reduction in ALC use by participants who were part of the SIPA (the French acronym for System of Integrated Care for Older Persons) intervention involving comprehensive integrated care for older adults in Montreal. Caregivers reported greater satisfaction with the care received, patients reported no difference in satisfaction, and overall costs were not significantly different from the control group. The study authors note that their findings are consistent with a similar program in the United States known as Program of All-Inclusive Care for the Elderly (PACE) (Rich et al., 1999).

In the UK, Baumann et al. (2007) conducted a qualitative study which describes the characteristics of services in six jurisdictions in the UK which have been shown to be top performers in reducing the occurrence of delayed discharge. This study involved interviewing 42 health and social services staff working in these jurisdictions to identify a range of service elements that participants felt contributed to avoidance of delays. In particular relevance to the present study, five suggestions were made at the organizational level regarding internal hospital processes: establish teams to prevent avoidable admissions (e.g. in the ED); establish discharge teams to support nurse discharge planning; develop systems for close monitoring and communicating patients' progress; develop and apply robust patient choice protocols; and ensure availability of responsive transportation and discharge lounges. The study also presented several suggestions related to the relationship between hospital and community services staff including the development of an interagency discharge protocol, developing a simple and

efficient early notification system of estimated discharge date, and joint monitoring of individual discharges and weekly assessment of delays.

The Importance of Patient and Family Perspectives on ALC

The preceding discussion has employed the framework of Glasby (2004) to examine literature related to ALC in order to better understand and respond to the problems posed by ALC. According to Glasby and colleagues (2006), effective responses to these problems must be guided by evidence that includes a patient and family caregiver perspective, of which there is very little at this time. On one level, such evidence is useful to guide strategies to improve the patient and family experience given that many aspects of that experience have been shown to be negative or unsatisfactory in existing qualitative research documenting experiences of ALC (Doleweerd & Berezny, 2009; Kydd, 2008; Swinkels & Mitchell, 2009). In addition to the communication difficulties mentioned earlier, these experiences also include inadequate participation in discharge planning (Swinkels & Mitchell), immobility and inactivity (Kydd; Swinkels & Mitchell), and anxiety about the future (Kydd).

However, evidence which includes the patient and family perspective is also important to guide comprehensive, well informed solutions whose goal is a reduction in the actual occurrence of ALC. Glasby and Littlechild (2001) found that older patients who had been deemed to be inappropriately admitted to hospital were able to provide a much more holistic analysis of the circumstances leading to their admission than standardized clinical review instruments. The patient perspectives also contradicted assumptions held by healthcare professionals regarding the reasons for patient

admissions. In the area of ALC, the perspective of patients and family caregivers may in a similar way provide valuable and insightful analysis of the problems leading to the delay in their discharge from hospital.

Three qualitative studies explored the experiences of patients or family caregivers related to the phenomenon of ALC (Doleweerd & Berezny, 2009; Kydd, 2008; Swinkels & Mitchell, 2009). The study by Kydd, based in the UK, used an ethnographic approach involving participant observation to explore the experiences of older patients who were frail and awaiting discharge from an acute care hospital ward to a care home. This study did not involve the recording and transcribing of interviews with patient participants but rather used the investigator's interpretation of their experience through the use of field notes. The study found that participants were anxious about their futures.

Using a phenomenological approach, a second UK study by Swinkels and Mitchell (2009) was based on audiotaped single conversational interviews with 23 patients aged 65 years or older from three hospitals in the South of England. The length of delay at the time of interview ranged from three to 94 days, and six of the 23 patients were delayed while waiting for LTCH placement. The major theme about involvement in planning for community discharge focused on the fact that a number of participants willingly or unwillingly relinquished involvement in the discharge planning process. For example, one participant said, "I'll leave things to my daughter to sort out. She's far more capable than I am" (Swinkels & Mitchell, p. 49). For others, this relinquishment was found to be connected with low mood, frustration or even anger and was seen as an expression of the patients being disempowered.

In Ontario, a report by Doleweerd and Berezny (2009) included a total of 21 interviews conducted mostly with family caregivers rather than patients themselves in caregivers' homes at some unspecified time after the patients were transferred to a LTCH. The patients' age ranged from 55 to 92 years. Overall, the report provided insight into the experiences of the family caregivers but did not clearly document the firsthand perspective of patients regarding these experiences. These interviews occurred some time after the experience with ALC and, once again, were based on single interviews.

In summary, this literature review has positioned the problem of ALC as it relates to older adults in Canada as a hospital situated symptom of problems in the health and social care systems intended to meet the non-acute needs of older adults. The problems related to ALC are understood to be a complex constellation of factors that exist within three levels of concern at the individual, organizational, and structural level. Current research into possible solutions to the problem of reducing the occurrence of ALC for older adults is limited though comprehensive approaches of integrated care seem to hold some promise. This literature search has found only three studies which examine the experience of ALC from the perspective of the older patient and their family caregiver. This perspective is important not only to guide strategies to improve the experience of ALC for patients and family caregivers but also to contribute to a holistic analysis of possible solutions intended to reduce the occurrence of ALC. Unlike the existing studies, the purpose of the present study is to examine experiences of ALC through time while participants are in the midst of the experience while also exploring the significance of place and a series of places.

CHAPTER 3: METHODS

Narrative Methodology

In order to better understand the experiences of older hospitalized patients and their family caregivers after the patient is designated as requiring ALC, I chose a qualitative approach. The particular method used in this study is a narrative method known as the Three Dimensional Narrative Inquiry Space Approach developed by Clandinin and Connelly (2000). This method has been used to guide all decisions related to research design.

Assumptions Underlying the Narrative Approach of this Study

Pinnegar and Daynes (2007) note that narrative inquiry is an approach to qualitative research that sees story or narrative as central to expressing and shaping human experience. It is quite an old practice in that "human beings have lived out and told stories about that living for as long as we could talk" (Clandinin & Rosiek, 2007, p. 35). Narrative inquiry in the social sciences has intellectual roots in the humanities and other related fields (Clandinin & Rosiek). In recent years, narrative approaches have developed in a wide variety of social science disciplines including history, anthropology, psychology, cultural studies and sociology, and are finding increasing prominence in the professions of law, medicine, nursing, education, and occupational therapy (Riessman & Speedy, 2007).

Narrative method provides an ideal framework with which to better understand patient and family caregiver experiences related to ALC. Story telling is the way that people make sense of, and convey to others, their own experience (Lieblich, Tuval-

Mashiach, & Zilber, 1998). As in the field of education (Clandinin & Connelly, 2000), narrative method is ideally suited to an important goal of healthcare research in general, that of improving human experience. As Frank (1995) points out, stories are by nature social, requiring a listener, and narrative method provides a mechanism to structure that listening as inquiry. Frank also notes, however, that stories get told in a larger societal context that influences which stories are told, and how they are told. In this spirit, the goal of the present study is to employ narrative method as a means to surface stories about ALC that include the experiences of older adults and their family caregivers.

The Three-Dimensional Narrative Inquiry Space Approach

Rooted in the *theory of experience* put forward by John Dewey, a philosopher and famous thinker in the field of education in the United States in the first part of the 20th century, Clandinin and Connelly (2000) developed the *Three-Dimensional Narrative Inquiry Space* approach to narrative research in the field of education. This approach is used to think about the data that is gathered in the form of transcribed narratives and includes three aspects: *interaction* of the *personal* and *social*, *continuity (*or *temporality*, that is, *past, present and future)*, and *situation (*or *series of places)*. The personal refers to "a person's internal conditions, his or her hopes, feelings, aesthetic reactions, and moral dispositions" (Clandinin & Connelly, p. 50) and this inward aspect interacts with the outward environment including the people around them. Continuity or temporality refers to the inquirer's attempt to place the storyteller's overall experience in the context of experiences from their past, present, and anticipated future. Finally, the situation or place

in which experiences occur is very important in developing an understanding of the stories which are told.

The Three-Dimensional Narrative Inquiry Space approach was selected to guide data collection and analysis in this study because it addressed some of the key aspects relevant to the phenomenon of ALC. First, the emphasis on personal and social interactions guided inquiry into the participant's feelings and values, and exploration of their interactions with others, including health care providers. Second, as reflected in the research literature, older patients awaiting placement under ALC designation are in the midst of a very significant time of transition in their lives which often includes a move from independent living in their own home to a supportive care environment such as a Retirement Home or LTCH. This narrative framework with its emphasis on the importance of place was well suited to guide interview questions and data analysis by accounting for the significance of place in the experiences of participants. Finally, the emphasis on temporality helped shape my understanding of how the present transitional experiences of participants are continuous (or not) with past and future experiences.

Setting

The setting for this study was a large, urban, university affiliated teaching hospital in the South Central region of Ontario which provides a full range of health care services including tertiary and quaternary acute care, chronic care, and mental health care. Participants were recruited from within the Internal Medicine service on five different wards in the hospital. Four of these were acute care wards, and one was known

as the ALC Ward which was specially designated for those patients in the hospital who ended up having a protracted hospital stay after designation as requiring ALC.

Participants

All patient participants for this study were recruited from the population of older patients admitted to the hospital under the Internal Medicine service. Patients were eligible for inclusion in the study if they were 75 years or older, designated as requiring ALC within the last 30 days, able to speak and understand English, admitted from a private home, and having a high likelihood of application for placement in a LTCH, Retirement Home or Complex Continuing Care facility. Patients were excluded if they: were designated as requiring ALC-Palliative or ALC-Rehabilitation, were referred to Palliative Care, were not aware of a probable plan for placement outside of their present home, had severe dementia or a current delirium, had undergone a procedure where a family member had given proxy consent, or were under the order of a Public Guardian. Because I was also working in Palliative Care at this same hospital at the time of the study, those patients who were presently being seen, or had in the past been seen, by Palliative Care were excluded in order to avoid real or perceived threats to the level of care received during their hospital stay.

Family caregivers of patients were also included in the study in order to elicit their own experience of the time that the patient was under ALC designation at the hospital. Eligible patients who consented to participate in the study were asked to identify a person who could be approached to participate as a family caregiver. Family

caregivers were included if they were 18 years of age and older, and able to speak and understand English.

Study inclusion criteria were later revised to also include family caregivers of patients with severe dementia to try to better understand their experience and to represent the perspective of patients with severe dementia who were designated as requiring ALC. These family caregivers were the persons who were formally identified as the substitute decision-maker for the person with severe dementia. Unfortunately, no family caregivers meeting these inclusion criteria were recruited to the study.

Recruitment and Sampling

Recruiters for this study were professional staff members involved with the care of patients on the internal medicine service after the designation of the patient as requiring ALC. Recruiters included two Nurse Practitioners, eight Social Workers, and a Clinical Nurse Specialist working with the Geriatric Assessment Team. Throughout the three month period of active recruitment, a weekly list of all internal medicine patients meeting criteria for age and ALC designation was generated in the social work office. On a weekly basis, I met with recruiters to review this list and to answer any questions related to the screening process based on the inclusion and exclusion criteria (see Patient Screening Form and Family Caregiver Screening Form in Appendix A). The recruiters then made an initial approach to any potential participants using either the Patient Recruitment Script (see Appendix B) or the Family Caregiver Recruitment script in the case of patients who were excluded from the study for reason of severe cognitive impairment (see Appendix C). The recruiter then introduced eligible patients or family

caregivers to the study, and asked if they would be willing to be approached by me about participating.

In the narrative approach employed for this study, the sampling strategy is meant to allow in-depth exploration of the experiences of participants. To this end, I used a purposive sampling approach to identify a small number of information-rich cases in order to generate meaningful insights into the research question (Patton, 1990; Schwandt, 2007). The particular approach I employed can be understood as a form of criterion-based sampling whereby specific inclusion and exclusion criteria were used to guide the selection of participants (Patton). My intent was to sample a broad range of experience within the older ALC patient population including but not limited to: a) demographic characteristics (e.g.gender); b) medical characteristics (e.g. comorbidities, cognitive function, presenting condition); c) place (living situation before hospitalization and destination following discharge); d) amount of social support; and e) specific aspects of ALC stay in hospital (e.g. duration, positive or negative care experiences).

In the end, all eligible patients who consented to participate in the study were accepted on a sequential basis over the three month period of active recruitment for this study. I began recruitment in the summer of 2010 and was not able to identify any eligible participants using a criterion of time since ALC designation ≤ seven days. As a result, in the fall of 2010 I sought and received approval from the Research Ethics Board for two revisions intended to expand the pool of potential participants by increasing the time since ALC to ≤ 30 days and by including family caregivers of patients with severe dementia in the study. I have labelled this time from early October 2010 to mid January

2011 as the time of *active recruitment* during which all successful recruitment occurred following the above adjustments to the inclusion criteria.

Process Consent

Given potential concerns about the level of physical and cognitive functioning in this vulnerable population of hospitalized older adults and their resultant capacity to freely consent to this research, I employed an approach to consent known as the *process consent method* (Dewing, 2007). The purpose of this method is to specifically address the problem of inclusion of persons with dementia in research studies. The central idea of this approach is that consent is an ongoing process that occurs throughout the research process and is grounded in the relationship between the researcher and the participant. Through this process, the researcher assesses at each encounter, and even throughout the course of a given encounter, that ongoing consent is being provided in a way that is consistent with the consent that was provided initially. It includes efforts to monitor the ongoing well-being of the participant and whether that well-being is in some way eroded by the research process. This can be judged by collection of data from the person directly or from others familiar with the person to identify signs of any decrease in the person's level of well-being as a result of the research process.

After the initial visit by a recruiter in their circle of care, I approached potential participants to give an explanation of the study. While explaining the study using the Patient Information Letter (see Appendix D), I followed the framework of Sherratt, Soteriou and Evans (2007) to assess the patient's capacity to provide informed consent by assessing their responses to my explanation about the study. Once deemed to have

capacity, and if the patient was willing to participate, I confirmed the name and telephone number of the family caregiver to be approached about participating in the study and, at a later time, contacted the family caregiver by telephone (see Telephone Script for Family Caregiver Contact - A in Appendix E) to introduce the study and seek their participation. Only one family caregiver of a patient enrolled in the study declined to participate in the interview process. I used the Telephone Script for Family Caregiver Contact – B (see Appendix F) to telephone family caregivers of patients who were excluded from the study for reason of severe cognitive impairment.

At the beginning of the first interview with the patient, I provided written and verbal explanation of the study procedures, risks and benefits, and then obtained signed consent (see Patient Consent Form in Appendix G). During the interview, demographic information was gathered from the patient using the Patient Biographical Information Form (see Appendix H). I used different information, consent, and biographical information forms for family caregiver participants (see Family Caregiver Information Letter in Appendix I, Family Caregiver Consent Form in Appendix J, and Family Caregiver Biographical Information Form in Appendix K). At subsequent interviews, I reminded all participants of their right to withdraw from the study at any time, and conducted the ongoing assessment as described by Dewing (2007) to ensure ongoing consent to proceed.

Data Collection

The Interviews

The primary form of data collected for this study was digital audio recordings of individual participant interviews. In total, 21 interviews were conducted with nine participants. An interview guide was used to conduct semi-structured interviews (see Patient Interview Guide in Appendix L and Family Caregiver Interview Guide in Appendix M). The interview guide was created using the Three-Dimensional Narrative Inquiry Space approach with its emphasis on time, place and interactions as a framework. As well, questions were chosen based on my review of the literature and what was already known about experiences related to ALC. I pilot tested the interview guide with a friend who had been a family caregiver for her mother who had been designated as requiring ALC about three years before the start of the study and found that the guide elicited meaningful responses for the interview. In some cases during the actual study, the prepared questions were modified or reworded in order to accommodate communication difficulties with some of participants, for example, by hand writing in large text a summary of the question for a patient who was hearing and visually impaired. I also used an amplifier to aid communication with participants who were hearing impaired.

The Three-Dimensional Narrative Inquiry Space approach of this study views time as a central and important dimension of experience (Clandinin & Connelly, 2000). For this reason, I sought to conduct at least two interviews separated in time for all

participants. In the end, I was able obtain multiple interviews with all participants except one patient and one family caregiver.

As many patient participants had very limited mobility, I carefully negotiated a place and time for interviews that realistically balanced the need for confidentiality and the wishes of the participant within the given limitations of the hospital setting. In most cases, I was able to conduct the interviews with participants in a private location on the ward, such as an office or meeting room, by seeking staff member assistance with transfers to a wheelchair. In the case of three patients, the final interviews were conducted, at their request, in their bedroom with their room mate present in the next bed. Two of the family caregivers on the day of patient discharge requested final interviews in public areas, one at the hospital coffee shop and the other at a fast food restaurant near the LTCH to which her father was being transferred.

Field notes

The other source of data was extensive field notes that I kept throughout the entire study period. These field notes recorded my impressions immediately following each interview or interaction with study participants, observations about the setting, and reflections on my own experience of conducting this inquiry. I also documented all questions, interpretations, and decisions related to the process of reworking and analysing the field texts.

Data Analysis

The data collected from the interviews and field notes as described above are collectively termed the *field texts* by Clandinin and Connelly (2000). The general

approach to analysis of field texts was guided by the Three-Dimensional Narrative Inquiry Space approach. Overall, the field texts from each participant were re-storied by analyzing them for experiences and the key elements of the story, that is, time (past, present and future), place or a series of places, and interaction (personal experience and the participant's interactions with other people in their social context including family, friends and health professionals among others).

The process of analyzing and re-storying the field texts began with review of the transcripts from the first interview for each participant. Re-storying involves a complex set of steps whereby the field texts are analyzed using holistic content procedures (Lieblich et al., 1998) to create a final storied account of participant experience (Clandinin & Connelly, 2000; Ollerenshaw & Creswell, 2002). Through this initial process of re-storying, I created a three to five page summary of the interview written in the first person from the participant's point of view using almost solely the words of the participant arranged chronologically and/or thematically to create a narrative. This narrative was reviewed with the participant at the next interview and any comments and suggested revisions noted. The creation of these summaries constituted the beginning of what is known as the development of *interim field texts* (Clandinin & Connelly). All interim field texts were reviewed with my thesis supervisor as well as the narrative methods expert on my committee.

Next, I combined all of the story summaries for each participant into a continuous first person narrative from the participant's point of view, again using only a few words of my own to connect and clarify ideas in the narrative. As per protocol, from this point

forward, none of the process of re-storying was checked with the participants in the study since the patient would have been discharged from hospital. Each combined narrative was then re-storied into a first person contextualized account from my point of view. This contextualized narrative included my re-storied summary of their words along with observations gleaned from my field notes about different aspects of the context for that participant. These contextual observations included my interpretations of things that were said by participants, observations about the setting or environment, and comments about relevant events that were occurring within or outside the hospital at that time.

At this time, the contextualized narratives ranged in size up to 34 pages for each participant. All of these narratives were shared with all members of my thesis committee. I then conducted a process of *holistic content analysis* as described by Lieblich, Tuval-Mashiach, and Zilber (1998) which involved the identification of a global impression, foci and themes for each participant through a repeated rereading of all the transcripts and contextualized narratives. This analysis was summarized in research memos that were shared with my entire thesis committee.

Next, I began a more traditional qualitative analytic process identified as *categorical content analysis* by Lieblich, Tuval-Mashiach, and Zilber (1998) focussed on the transcript data which resulted in the creation of themes and sub-themes that were common across participant stories. In the final stage of re-storying, the contextualized narrative for each available patient and family caregiver pair were combined into a single first person narrative in my point of view. The decisions I made in the re-storying process were guided by the results of both processes of content analysis described above. As

well, I now chose direct quotations from the transcript data to replace my own narrative summary of their words. The final narrative or story included the experience of both the patient and the family caregiver in a much more condensed format. All of these narratives were then reviewed with the entire committee and final edits made to arrive at the stories as presented in Chapter 4: Findings: Stories of the Participants. The results of the categorical content analysis are presented in Chapter 5: Findings: Themes Across Cases.

Strategies to Ensure Rigor

Nelson (2008) suggests a set of minimum standards by which quality can be assessed in qualitative approaches to nursing research including explicit reference to research strategies intended to ensure methodological rigour. I addressed issues of rigour in this study by incorporating several strategies suggested by Kirkpatrick (2005) which are intended to ensure rigour in narrative inquiry.

Maintaining an audit trail. An audit trail "provides evidence that …helps the peer reviewer or auditor to trace the textual sources of data back to the interpretations and the reverse" (Wolf, 2003, p. 175). Throughout this study, I kept a *reflexive research journal* (Nelson, 2008) that recorded rationale for decisions that I made about the ongoing research process including the analysis and interpretation of the data.

Part of the audit trail process includes the idea of *thick description* whereby the research account "goes beyond mere fact and… presents detail, context, emotion, and the webs of social relationships that join persons to one another. It establishes the significance of an experience… for the person or persons in question" (Denzin, 1989, p.

83). The extensive process of re-storying the field texts employed in this study has been intended to arrive at findings that present such thick description.

Congruence between chosen methods and a narrative approach. Throughout the planning for this project, I chose research methods and strategies that were intended to result in a research design that is congruent with the narrative approach that underpins this study (Clandinin & Connelly, 2000; Kirkpatrick, 2005). For example, the research question, the techniques related to interviewing of participants, and the analytic procedures were all derived from a narrative approach. Questions in the interview guide were structured to elicit from participants accounts which spanned time (past, present and future), place (home, hospital, and planned placement location), and the personal (internal hopes, feelings, aesthetic reactions, and moral dispositions) in interaction with the physical and social context in which participants were located. The dimension of time was also structured into the method by seeking two or more interviews to better understand the evolution of participant experiences over time. Finally, interviews occurred in the hospital setting where patients were located, in the midst of the experiences they were describing.

Participant selection criteria. The broad purpose of this study was to provide insight into the experiences of participants in relation to the phenomenon of ALC. To this end, I chose a narrative approach which is well suited to exploring in some depth the experiences of a few individual participants over time. The criteria for the selection of participants were based on information in the existing literature about participants who might be able to provide rich information related to the experience of ALC. This

sampling strategy within the narrative approach is congruent with purposeful sampling of participants in other qualitative designs (Forman, Creswell, Damschroder, Kowalski, & Krein, 2008).

Prolonged engagement. Narrative inquiry rests on the foundation of a meaningful relationship between researcher and participant that is oriented toward the purpose of research (Clandinin & Connelly, 2000). As well, narrative inquiry views the participant setting as key to understanding the stories that participants relate about their experiences (Kirkpatrick, 2005). Prolonged engagement, then, is an important way of ensuring that the researcher has developed a credible understanding of the patient experience over the course of the study. In this study, I conducted two or more interviews with seven of the eight participants and my total time of engagement with these participants ranged from three to almost seven weeks. The encounter with one participant lasted only five days and resulted in only one interview.

Processes of checking and confirming. Member checking, a frequent strategy for enhancing rigour in other qualitative approaches (Forman et al., 2008; Nelson, 2008), is an important part of narrative method. Kirkpatrick (2005) suggests that the Three-Dimensional Narrative Inquiry Space approach views participant checks as less a question of correct reporting than a question of identity. When reviewing a narrative with a participant, the questions guiding the feedback process are of a more general nature: “Is this you? Do you see yourself here? Is this the character you want to be when this is read by others?” (Clandinin & Connelly, 2000, p. 148).

I was able to review my narrative summaries of the first interview with eight of nine participants. One family caregiver was not available to meet at any time after the interview to review the summary. Also, I was able to review the final interview with only one participant before discharge. In total, 13 of 21 interview summaries were reviewed in this way. As well, as described earlier, I confirmed my own emerging interpretation and analysis through a regular process of review with my thesis committee.

Broadening the feedback. Broadening the feedback in narrative inquiry involves sharing the evolving research story with others outside the immediate context of the study. At the time of this writing, I have received feedback on the interim findings at three gerontology conferences, two provincial and one national. This feedback on interim findings of the study was very helpful in clarifying the process of re-storying participant interviews because it helped me better understand one important audience for this research (health professionals) and what elements of the emerging stories resonated most powerfully with their own experiences.

I have also discussed the findings with a committee examining ALC policy at the hospital where the study was conducted. This process was very helpful in thinking in concrete terms about the implications of the study for practice and policy at the hospital where the study occurred, and thereby aided reflection on implications for wider concerns beyond this local context. For instance, the committee was surprised about the theme describing participants not knowing about the placement process given that the hospital had process of care data indicating that generally such information was being shared with patients and families. This led to an exploration in the discussion section of

this paper about possible explanations for the disconnect between hospital data related to processes of care and these findings related to patient and family experiences of the care received.

Ethical Considerations

I obtained approval to conduct this research project from the Research Ethics Board which was associated with the hospital at which the study was conducted and jointly administered with McMaster University. Given their recent acute illness and their reduced physical and/or cognitive functional abilities, participants in this study were a vulnerable group. As such, great care was taken to protect their rights and to minimize risks to participants. The approaches described above for assessing participant's capacity to give free and informed consent (Sherratt et al., 2007) and the process consent method (Dewing, 2007) were intended to ensure that a robust procedure was followed in seeking the participation of patients in this study.

The ethical principle of justice urges the inclusion of persons with dementia in the process of research which is related to their life experiences in order that they have better access to the potential benefits of such research (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). An unfortunate result of the concern to protect this vulnerable group from risks related to research has been a reliance on proxy reports of their experience. There is growing evidence that such proxy accounts may not accurately reflect the perspective of people with dementia with some studies for instance showing that proxies underestimate the subjective quality of life experience of the person with dementia (Hellstrom et al.). This study sought to address this concern by trying to actively include patients with mild

to moderate dementia because they are a group significantly impacted by the phenomenon of ALC (CIHI, 2009). At least one of the participants in this study presented with noticeable but not severe cognitive impairment that was not related to delirium. This patient clearly and consistently confirmed her ongoing desire to participate in the study and her family expressed no concerns about her participation.

An area of ethical tension that I experienced during the period of data collection related to my *dual role* at the hospital as Principal Investigator for this study as well as a clinician. At times, I felt uncomfortable about what I was hearing during some of the interviews. This discomfort was most prominent in the case of two of the family caregiver interviews where the participants expressed great distress related to their care giving roles. This discomfort had to do with questions I had about my duty in this situation and how I might respond. Did I need to intervene in some way? How might I do this? Would I jeopardize the nature of my researcher-participant relationship if I did intervene clinically? In the end, upon careful debriefing with my supervisor following these interviews, I felt confident that both participants were not in any current jeopardy and had appropriate access to needed supports, and that my responses during and after the interviews were appropriate in my role as researcher.

However, it was also apparent that my role at the hospital facilitated aspects of the study, particularly recruitment. My dual role, then, enabled the inclusion of the older hospitalized patients in important research related to the care received by this population. Thus the ethical principle of justice, in the sense of all members of society having

opportunity to benefit from research findings, was probably enhanced through this same dual role.

I had several channels of accountability to ensure that I adhered to ethical approaches in my conduct of the research. First, all aspects of the study protocol were reviewed and approved by the Research Ethics Board for the hospital. Second, I fully and frequently reported all activities related to the research to my thesis supervisor. The thesis committee was a second avenue for review of ethical issues related to this study. Finally, I reported regularly to the Local Principal Investigator for this study who was also my clinical supervisor at the hospital in my work role.

CHAPTER 4: FINDINGS - PARTICIPANT STORIES

Overall Description of Study Participants

There were nine participants in this study, five patients and four family caregivers. In four of the cases, interviews were conducted with both a patient and the person they suggested as a family caregiver. The final case, the story of Frank, involves data from an interview with the patient only as that family caregiver in the end declined to participate. [Note: The names used for the participants are pseudonyms.] In total, 21 interviews were conducted with two or more interviews occurring for seven of the nine participants. The patient participants ranged in age from 82 to 89 years (mean age 84 years) and included three men and two women with three married, one single and one widow. The family caregiver participants ranged in age from 48 to 59 years (mean age 54 years) and included three women and one man with two single, one married and one in a common law relationship. The patients were enrolled in the study between three and 30 days after being designated as requiring ALC and interviewed about every two weeks until discharge with the longest follow up for a participant being eight weeks. The total time period covered from the time of enrollment of the first patient up to the discharge of the last patient was ten and a half weeks. Appendix N provides a brief background summary of each patient and family caregiver participant.

Stories of the Participants

In the next section, five stories are presented summarizing the five patient/family dyads followed for the study. The first four stories interweave the narratives of the patient and their family caregiver to produce one account of their shared experiences.

The Story of Dan and Sarah: I Never Thought I'd End up my Life Like This

****** *Dan* *******

I first met Dan (age early 80s) in his bedroom on the ALC Ward, a ward specially organized to accommodate patients who had been designated as requiring ALC. As I pushed his old blue vinyl geriatric wheelchair to the TV lounge, he greeted various staff members along the way. He was a short man, broad in stature, wearing a hospital gown with exposed swollen legs propped up with pillows. He had large round forearms and swollen hands with short fingers bent at unnatural angles. He was shaved and his hair was nicely combed.

Although the recruiter had warned me that Dan was hard of hearing, I had no idea how difficult it would be to communicate with him. I wondered what people outside the closed TV lounge door thought as I yelled questions into the amplifier I had brought along for this purpose. Fortunately, his literacy was quite good, though limited by scratched and dirty glasses bearing a prominent piece of tape across the bridge. By hurriedly scribbling questions on paper, using exaggerated facial expressions, waving my arms and gently touching his arm, I guided him through all three interviews.

Dan began with an account of himself as "an athlete and a worker." He spoke of learning to box as a child of 14 years in order to defend himself as an under-aged worker, forced by his father to earn money to support the family. He explained that his father "had no use for us except to work and bring home the money and then he would steal anything we had." He described his experience of getting married and leaving his

childhood home by proclaiming that "The bird's flown the coop, I'm gone, to have my freedom."

Prior to this hospitalization, Dan had been living at home with his wife and daughter. Problems with his feet meant he couldn't walk, and so his daughter forced him to go to hospital. Dan had terrible memories of this experience, and he felt very upset with his daughter about this.

> The next thing we know…two ambulances, two, that means four people coming to get my wife and I... I hugged her and she was crying, she said, "They're coming for us!" I said, just like I heard about the last war, the ghettos, they're coming for us… Next thing I knew a blanket was wrapped around me, threw me down on a stretcher, tied me on a stretcher, down the bumpy stairs. And my wife screaming and yelling, 'Leave him alone! We are together and we are happy! Just give us our food, our medicine and a wash!

***** *Sarah* *******

In light of the anger he expressed about his daughter, I was somewhat surprised when Dan suggested Sarah (age late 40s) as the family caregiver contact for the study. When we met for the first time in her father's bedroom, I was initially struck by the comfortable interaction between them. However, as we were leaving the room for the interview, he started telling me he wanted to find out who signed the papers to have him abducted because he was surely going to prepare a lawsuit and needed to know who it was! At this point, Sarah became noticeably distressed and, aware he couldn't hear well, talked quietly over his voice and, nervously laughing, explained that "He's always like this with people, paranoid."

The first interview with Sarah took place in the staff room on the ALC Ward about a week after the first interview with Dan. Like her father, she was short in stature

with rounded forearms and short fingers. She had short to medium length straight brown hair, and a kind face with rather furtive eyes.

Sarah recounted her experiences in caring for her parents with much emotion. Her description of the home and her father's situation was very different from Dan's account. When I asked about her father's life before coming to hospital, she began by saying, "He didn't have a life" and went on to explain that he hadn't even been out of the house for three or four years. She had always lived with her parents but took over direct care giving for both parents when her mother got sick and had her foot amputated about a year earlier. During that time she was working fulltime during the day and then would come home and prepare meals for her parents with Community Care Access Centre (CCAC) coming in three days a week to assist her mom. Initially, this worked fairly well, as her father was able to keep an eye on her mom and she was able to help him with tasks he found difficult to do: "So they were working like a little team."

Then she noticed a significant change in her father, and thought that he might have had a stroke.

> He started screaming at me because … he was in such pain all the time and he couldn't move, so he just laid there on his bed … And then I was feeding him, I'd bring porridge up when he was lying down, I didn't realize I was making things worse inside. Because I guess … he must have got the pneumonia from laying down eating. And I guess I was at fault because I just kept feeding him food.

Sarah went on to describe the breakdown that she suffered as a result of the stress of caring for both her parents during this time.

> Then I took a spell. I was very upset about stuff and I ended up here myself in this hospital … I call it the psych ward … she said

> … 'You need to get people to help you, you need somebody for your dad.' So I said okay. She said, 'You've got to promise me Sarah, you have to do it because you're getting caregiver burnout' … Like normally I should be able to handle these things, but I was breaking down crying and I wanted to kill myself and all that stuff.

On the heels of this breakdown, Sarah made the decision to have her father admitted to hospital. Despite the fact that she feared he would die if she didn't do this, she felt like a "failure" because he didn't want to be there, and she was scared about placement for both her parents, saying "I guess it's an old thing, I know the government has changed a lot, but I'm scared they're going to get abused."

****** *Dan* *******

During the first two interviews, Dan likened his hospitalization to an imprisonment and a hostage taking: "They put me in a room, scrubbed me down, shaved me, trimmed my hair, put the gown on. I don't have no clothes, I don't have a penny to my name, just a convict." When first admitted to hospital, Dan's wife, who has advanced dementia, was designated for crisis placement and within a week was admitted to a LTCH. Dan said the hardest thing about hospitalization was being separated from his wife. I asked if he had spoken with her and he said, "My daughter had a …phone and she said … 'There's mom'… I could tell her voice, very gentle and sad. She said … 'Wish you were here,' I said 'I do too.'"

All interviews with Dan were filled with distressed comments about his experiences with patients with dementia who were also staying on the ALC Ward and his concern for his safety and privacy. Although his language around these interactions was quite extreme, I understood the concern he was feeling. My field notes at that time

described a number of patients who had one-on-one accompaniment because of wandering. A few of these patients were at times quite aggressive verbally. Initially, I also felt uncomfortable on the ward having been confronted verbally by a couple of the same people that Dan refers to in the interviews.

> The experience is terrible in here, they have no security… loonies walking around free that they could come in your room. I woke up one night and that woman was standing over here, she was standing at the foot of my bed… she just stood there and glared at me. And then the one guy, she must have had a boyfriend or something, … I was laying in a chair like this in the family room and… he come over and wants to beat me.

Dan commented quite favourably about the care he received from the staff on the ward. He appreciated the assistance he received with personal care and feeding, and said that the woman who took him for a shower once a week did this "just like a mother would."

Dan was frustrated that there was not more attention paid to his inability to walk. "The doctor's not listening here. I came here for my legs to walk, they're puttering around with my bladder." He was quite disappointed because he didn't walk "at all. I just lay in the bed and they use that hoist thing and lift me up and put me in the wheelchair". He said he only got out of bed about two and a half hours a day.

Although earlier on Dan had joined in on planned activities in the family room, he no longer felt comfortable "because all these weirdoes are down there and they don't do nothing, they just sit there and stare at yah." He said he might have enjoyed playing cards with someone in his bedroom but felt that that would not work out because he was certain that one of the wandering patients would come and disrupt the game. As a result,

he spent almost all of his days in his bedroom, mostly in his bed where he watched TV. "Without the TV here, there is nothing, just the bare wall to look at."

***** *Sarah* *******

Sarah was not pleased about communication with the hospital regarding matters related to her father's care. She said that neither she nor her sister were informed when he was moved to Ward ALC. One day, she arrived at his previous location and couldn't find him. She said, "What the hell's going on, like one time he's in this one and then, I thought they were going to start those musical beds again like they generally do." She was also critical about not receiving timely medical updates. "I just wish they would notify me more about what's going on … I didn't even know that he had pneumonia [until her Aunt told her]."

Overall, Sarah said she felt like she was not treated well by the hospital and attributed this to the fact that her sister had accused her of neglecting her parents.

> My sister... said I didn't do enough… Since my father came in the hospital she's been talking about getting me charged with elderly abuse... [So] I feel that she [the social worker] was more aimed at my sister than me. And I thought after all these years, … I've been taking care of them … and they treat me like I'm a stranger here.

Sarah felt very disappointed about the lack of attention paid to her father's walking throughout his stay while under ALC designation and having seen the remarkable improvement in her mother's mobility after three months in the LTCH, felt that once her father was finally transferred, "the nursing home will probably have my dad up more going than the hospital." She was also upset that her father was charged an ALC co-payment given that the services provided did not meet her expectations of what a

LTCH would provide. “I was dumbfounded … They’re supposed to be a service for the patient … I totally get that they’ve got to make their money, but … five thousand dollars for twenty-six days?”

At the end of the first interview, Sarah told me she was planning to take a vacation at a southern resort in the coming week and we agreed to touch base after her return. I found out later that on the morning of the day she was supposed to fly out, “the City” arrived at her door and in a “whirl” took away piles of garbage bags stacked on her yard. She explained apologetically that she and her parents were all “hoarders” and that their house had been such a mess that after her parents were admitted to hospital and LTCH, the City had given her notice that she had to clean up the inside of her house. She had been working hard at this and made some progress on the inside but there was still much to be sorted in the many garbage bags that were taken by the City. She was furious about this and even called her Alderman but with no success.

After the first interview, Sarah spent a holiday week at a southern resort and she said she had a great time. She said “people were shocked” that she actually flew by herself, she made good friends there, and she even swam with the dolphins which she had always wanted to do. After the vacation, she felt much more positive about things and when she came home, said to herself, “Enough is enough, I’ve waited two months, … I feel they’ve done nothing for him.” She called the LTCH to ask why there was such a delay in getting her parents reunited and was told they had not received the papers yet. She then phoned the CCAC and “spoke sternly” saying she wanted her parents together

as soon as possible. She was surprised to get a call four days later saying that her dad was being transferred to the LTCH the next day at 10:30 am.

***** *Dan* ******

I was able to arrange a final interview with Dan in his bedroom about two hours before his departure the next day. When I asked how he was feeling about the upcoming transfer, his reply was a thoughtful and subdued reflection on the entire course of his life.

> Oh not very good, I don't trust, … sort of feel weird… I'm sort of scared that I lost everything and what else could get worse on me. I never thought I'd end up my life like this.

Dan went on to reflect on 50 years of work, times with very little money, then paying off his house, even having a little money to set aside, and now being forced into a LTCH by Sarah because she wanted their money. When I asked what he hoped for, he said "A better life, who's going to bury me?" and went on to tell a story he'd heard about how people who have died in a LTCH and have been cremated, have had their ashes dumped down a street sewer near the house where they used to live. He also said "I hope … they're [the LTCH] more up-to-date" and therefore better able to help him walk again in contrast to the hospital that he felt had done so little in this regard. About his upcoming reunion with his wife, his eyes twinkled mischievously as he said, "I'm going to pretend I don't know her, I'll say, who's this woman, what does she want!"

******Sarah******

Immediately following the interview with Dan, I met with Sarah at a McDonald's restaurant near the LTCH. She commented on the financial limitations that her parents faced, noting that her mom could not afford a semi-private room like her dad so they would not be able to stay in the same room together at the LTCH. The fact of this move had also prompted her to reflect on her own life and where she might live in the future:

> I know I have to get the house situated and get it cleaned out and maybe look at selling it and moving on… I've lived there thirty-two years and you know, I guess the thought of moving on… And now I've got to think about where am I going to live …I don't know what my future will hold … I'm in the air myself. But I'm kind of liking it … I kind of have my independence which is what I have been longing for since I was in my twenties. … But I realize now I have been through a lot. People who have known me for a number of years, even my sister has said, 'I think you have grown up in the last year.'

I felt grateful that Dan and Sarah were both willing to participate in a final interview on such an important and unsettling day. I walked her to her car, and wished her well. She then drove off to meet her father who we had seen, through an upstairs restaurant window, arriving via ambulance transport to the LTCH about 15 minutes before.

The Story of Teresa and Janice: Life is Passing you by, and You're not Going Anywhere

******* Teresa ********

Teresa (age late 80s) arrived at the TV lounge on the ALC Ward for our first interview, seated in an aging, powder blue, vinyl Geriatric Chair and accompanied by a Personal Support Worker (PSW). Teresa was an 88 year old woman, tall and thin, wearing a house coat over her hospital gown and sporting large, navy blue, air filled

protective boots extending to mid-calf with gauze bandages visible underneath. She had short gray hair, no glasses, and a piercing gaze in a mostly unsmiling face.

The first half of this interview included long periods of silence and brief answers followed by the guarded comment, “What else do you want to know?” As time went on, however, she shared more openly. Overall, she was pleased with the care she was receiving in hospital. When asked if she had any suggestions for improving the experience for patients designated ALC, she said, “No, I would think they [staff members] would be making the best decisions they could for the patient.”

Before this hospitalization, Teresa lived in the same house for 40 or 50 years, by herself since her parents died. Following retirement from a government agency at 65, her life centred on her church and her Roman Catholic faith. She attended church services regularly, and did many hours of volunteer work at the church. “I was on the go all the time. And I loved to walk, I walked all over the place, very seldom did I take a bus."

Although she doesn’t remember much about the incident, Teresa said she must have fallen in her house and been on the floor for about 20 hours before neighbours noticed and called the police. She does remember “the whole block” being out to watch the ambulance transport her to hospital. “I remember being in the ambulance because the neighbors were all out, the whole block, so I can remember that, but much more of that I don’t really remember.”

****** *Janice* *******

The first interview with Teresa’s niece, Janice (age late 50s) occurred in the nurse manager’s office on the ALC Ward about five days after the interview with Teresa.

Janice was of average height, had short, red hair and a friendly, outgoing demeanor. Like her Aunt, Janice was also quite involved with and in fact employed by her church. She began by telling a story about her own mother's funeral three years before when her Aunt, seated beside the coffin, said "You went out of turn." She said her Aunt Teri was practical and independent and didn't like "to be a bother on people… I never got into the house. I was always met at the door and we sat on the porch." Friends of hers had wondered how she could have let her Aunt "get into that condition" when in fact, with some frustration in her voice, Janice commented that "the only person who could tell my Aunt what to do was my mother and she deserted us [three years ago]." She went on to say that "since this all started, I've said to my mother, 'How dare you leave us to deal with this?'" It was clear, however, that Janice felt much affection toward her Aunt and did this care giving because she wanted to repay all the kindnesses received from her Aunt over the years.

Like her Aunt, Janice was very pleased with the care provided by the hospital. About information she and her Aunt might have needed about her hospital stay and plans for placement, she felt confident that "when they have something to tell me… they will contact me." She went on to explain that her Aunt was an intelligent woman and she was certain the hospital would discuss all these matters directly with her.

****** *Teresa* *******

Over the four interviews, Teresa commented frequently on her mobility. At the first interview, she pointed out that she was dependent on others to assist her to move out of the bed, for transfer to wheelchair, and then moved in the wheelchair. Seeing little

progress after four weeks under ALC designation, Teresa speculated that she would never again be able to walk and that the reason the doctors were not informing her about her disease prognosis was to protect her from the distress associated with this. She was disappointed, saying, "I like everybody to be straightforward … 'You're not going to be around long, get ready, be prepared.'"

By the second interview, Teresa had begun to participate in exercises and to walk a few steps with a physiotherapist. She was, however, frustrated by the intermittent nature of the therapy, including the lack of therapy on the weekends, saying to the therapist at the time, "There's really no purpose you coming if you don't come on a regular basis." She was hesitant to get her hopes up about the walking because if this didn't materialize, "the letdown is pretty hard."

By the third interview, Teresa was able to slowly push her own wheelchair up and down the hall. After some probing, Teresa explained that it was her initiative that largely led to this newfound mobility. Seeing other people on the ward propel their wheelchairs using their hands, she asked if she could do this herself and so, once assisted to transfer to her wheelchair, she was now much more free to move about.

Throughout the interviews, Teresa spoke about the challenge of having to wait for different things. This was most clearly conveyed in the second interview which was characterized by frequent complaints, in marked contrast to the first, more guarded interview. At the time of the second interview, she was still fully dependent for all transfers and needed someone to move her wheelchair "I feel myself that I complain too much and I feel sometimes [that] I like [too much] immediate attention." However, she

detailed numerous examples of waiting for care such as assistance with meal preparation, toileting and being put to bed. She also commented about the "inner strength" of other patients on the ward who were more disabled than her, observing that the amount of waiting that a person needed to endure seemed to increase with their degree of disability.

> I was wishing people could be more helpful to them because you have to always wait. Like if you're the more disabled to me you always have to wait till everybody is looked after. But um, with staff problems, who knows and they seem to be happy in their environment, like they're not discontented or grumbling or complaining. So they have some inner strength from some place, whether it's family or spiritual or what, I don't know.

Teresa attributed her complaining to "the inactivity: … when… you have nothing else to do, your thoughts are all on you", and contrasted this with her previous life which was full and active. She commented about the structured activities in the dining room, saying "they'll have crafts, pottery that I am not interested in." She described one day when the group was working together on a crossword puzzle but only two or three of the 10 people there were involved while the rest just sat, and she thought, "Well, isn't this silly…a waste of time." A simple activity that she would have found quite meaningful, she said, was simply having assistance to be wheeled up and down the hall to see different scenery and say hi to people because "at least you could see something going on … but I realize, you know, they don't have staff for all of this and I don't know how much volunteer staff they have."

The night hours on the ward were almost unbearable. "The days are long, the nights are longer, and of course in every room they have a great big clock that tells you

exactly what time it is to the minute. So your life is passing you by and you're not going anywhere." She described her experience of night time this way.

> The night hours are the worst, … you wake up and look at the clock and know the nurses are checking in at certain hours … Of course … you close your eyes and pretend you are sleeping because you don't want to be bothered with questions like, 'Why aren't you asleep?' There is nothing they can do about it … The day will pass the same as every other day and every other night, slow but sure …

Teresa felt badly about complaining "all the time." Our interviews seemed to be an important context in which she could voice these concerns since she said she was very reticent to complain to her nieces about these matters. She said she was really struggling with this newly discovered part of herself and spoke about this struggle in the context of her religious beliefs.

> You know, when you think of people throughout the world starving, children being molested and awful things happening in the world and yet you're complaining and I think, 'What must God think of you?' He put me on this earth for a purpose, this is the way he wants things to be, like why don't I say thank you God, I accept it, instead of carrying on like an idiot you know? ...I don't like that part of me [yeah] because I never thought in my life I would be one to complain.

Though many concerns were still present, the overall tone of the third interview was much more positive and hopeful than the previous two. Teresa began with a moving description of attending mass in the chapel at the hospital. "…it was really delightful, it was so long since I've been to Mass… it was really good." She said that a priest visiting to give her regular communion in her room happened to mention it. That afternoon, she wheeled herself down to the nursing station to enquire. Unfortunately, staff members there were unaware of the schedule for mass. Disappointed, Teresa pressed the point:

"Well, aren't you an information centre?' and they said, 'No, we're a nursing station.'" Undaunted, she eventually clarified the schedule for mass, and after two days, was able to find a volunteer willing to wheel her chair to the chapel in another part of the hospital.

****** *Janice* *******

The second and final interview with Janice happened about three weeks before her Aunt was discharged from hospital. Overall, she felt that nothing much had changed though she was very pleased that her Aunt was walking for the first time since being in hospital because this would help with her independence. She also noted that her Aunt had asked the physiotherapist, "Are you going to come every day and help me walk?" She was pleased and felt this indicated that her Aunt was engaged in her own care.

Regarding the plans for placement, Janice said that she hadn't heard anything about this. "Well they haven't approached us, so I'm surmising that she must reach a level of care or there must be vacancies available for her to go."

****** *Teresa* *******

The final interview with Teresa occurred in her bedroom while receiving a transfusion, about three hours before her transfer to the Assess and Restore Program. She explained that she was able to actually walk up and down the hallway with her walker. However, her overall concern about lack of assistance with exercise remained. "Here, I'm not getting any exercise." and hoped that the program at Assess and Restore would help her more.

This improvement in Teresa's function was mentioned a few days earlier by nurses on the ward who commented that it seemed she might be able to manage at a

Retirement Home level of care rather than LTCH, as they had first imagined. Unfortunately, it seemed that Teresa herself felt poorly informed about the plans for her care. She explained for instance that she did not understand the difference between a LTCH and a Retirement Home. She said she first heard about this general plan for transfer to Assess and Restore a month before this but was assured at the time that the move would not occur before Christmas. She was surprised then to be suddenly notified of the move about three days ago. She described her frustration as follows.

> P: I'm being moved to [the Assess and Restore Program] for therapy… I don't know what it involves… I don't know whether they have an infirmary. Or it's just like a hotel that you go and have a bedroom, and that's it? I have no idea…And I don't think they told my niece any more than they told me…
> I: Do you have any idea what the plan is?
> P: Not a whit, that's what I don't know… Will I be in bed all day? Will I be on my feet all day?

Although Teresa felt upset and ill prepared for the move, she emphasized that "I appreciate all they've done for me, you know. I'm well looked after, even though I don't know much of what they are doing." I spoke with Janice on the telephone that day and she said she was also disappointed with how little notice she got about this transfer.

Throughout the interviews, Teresa's view of the future remained grounded in her strong Roman Catholic faith. In the very first interview, I asked what she hoped for and worried about and this is what she said.

> I: What are your hopes for the future?
> P: Not much, not much, because you think what you're living day-to-day, you're in God's time, when is He going to call you? Would it be during the night, during the day? You don't know. But you have to face these facts you know, this is, this is what

> life's all about. Nobody is ever going to escape death, you're going to get it one way or another.
> I: What do you fear or worry about?
> P: I don't think I'm really worried about anything.

In the third interview, Teresa spoke further about the uncertainty she was feeling regarding her future and the many challenges she was facing and said "I think you get accustomed to things and you adjust or you go crazy, one or the other." Despite these challenges, and her awareness that things might never improve, her orientation toward learning to 'adjust' to the changes in her life suggested a willingness to continue to struggle to create a meaningful future for herself.

At the last interview, Teresa said she enjoyed participating in the study and noted with a laugh that it wasn't difficult because "I do all the talking!" She commented that it caused her to think about things she would otherwise have forgotten, and worried whether she was giving the right answers and conveying things the way "they really are."

The Story of Bob and Alan: I Don't Have a Future

****** *Bob* *******

The first interview with Bob (early 80s) was scheduled to occur on the Thoracic Ward where I had enrolled him in the study the day before. When I arrived on the ward, however, I discovered that he had been suddenly moved to the Cardiology Ward the previous evening. I found him in a private room on this ward and, in keeping with the sign outside his door, donned gown and gloves, and placed all interview materials in plastic bags before entering.

Bob was a short man, somewhat broad in stature with a round, unshaven face. He looked a little uncomfortable with the head of his bed only slightly elevated but stated

that he was feeling okay. Two of the fingers on his right hand were significantly disfigured by gout and it was challenging for him to sign the consent form because of pain and disfigurement in this hand. I pulled a chair up to the bedside, placed the bagged digital recorders on the over bed table between us, and pushed the room door shut to minimize the constant noise coming from the hallway. He had not been out of bed since his admission to hospital 35 days before.

In speaking about his life before coming to hospital, Bob said "I thought [I was in] great shape for a man my age. Yeah, I got around well, I walked every place." He spoke about how he liked to be with people, and how "every morning I used to go to the mall for coffee with a few fellows", in fact, getting up at 5:00 am for this cherished time with friends. He drove taxi for 30 years, and also worked in the restaurant business and at a sporting goods store. He said he enjoyed sports and music and explained that over the years, he and his wife, married for 61 years, had had seasons tickets to football games, hockey games, and the Philharmonic Orchestra.

About fifteen months previous, his wife, 82 years old, slipped at home and broke her ankle. He explained that she had "a little dementia" and he was upset that a decision was made at that time for her to be discharged to a LTCH instead of returning home with him. For the past fifteen months, Bob had been designated for crisis LTCH placement at the same LTCH with his wife. Although he was pleased with the care she was receiving at the LTCH, he was very upset and saddened about the length of time that he and his wife had been separated from one another, and described with much frustration the many "stories" he'd been told about how long he would have to wait until they were reunited.

He said, “they could be a little more careful about splitting couples up [in the first place].” Whenever we touched on issues related to this forced separation from his wife, he began to weep.

Just before this hospitalization, Bob was living alone in the house that he and his wife owned. His gout gradually made it harder and harder for him to walk. Suddenly one day, he couldn’t get out of bed and had forgotten to bring the phone with him. He waited until his son visited who then called 911 and had the paramedics take him to hospital.

****** *Alan* *******

When I first met Bob, he confidently said that his only son would be quite happy to participate in the study. He explained, however, that Alan (age mid 50s) was quite busy because he was out of town working throughout the week and returned to the city on weekends only. Using the three different numbers I was given, I eventually reached Alan. He said that he had been reluctant to participate but after reading the information letter and speaking with his dad, decided to do so.

This first and only interview with Alan occurred about two weeks after the first interview with Bob and 12 days before he was discharged from hospital. We met in a family room near the Flex Ward where his father was staying at the time. He explained that he had brought his mother along that day for an unexpected visit with his dad because she was hounding the staff at the LTCH for a visit with Bob. Alan was a large, heavy set man of 54 years with dark hair.

Alan was very emotional throughout the interview, at times red faced with anger and frustration, and when he spoke about his father, on the verge of tears. Though

articulate on many aspects of his experience, he was quite scattered during the interview and I found it difficult to piece together the chronology of his story. He said that about two years ago, his father had been in and out of hospital every six weeks or so over the course of a year. Whenever he was admitted, his mother, who has dementia, was home alone and found it very hard to cope. She made many frantic calls to Alan for help. Roughly 18 months before this, then, they started the process of seeking shared placement for his parents.

During one of the occasions when his father was hospitalized, about 15 months before the interview, his mother broke her ankle. She was admitted to hospital just before his father was discharged back home from the same hospital. At this point, Alan knew there was no alternative and began the process of crisis placement for his mother who spent one week in transitional care at another facility before being admitted to the LTCH where she now resides. Since living there, she had improved remarkably, “like Benjamin Button” as Alan described it.

Up until the past six months, his father had been doing quite well at home going out to visit regularly with friends and to visit Alan’s mother in the LTCH. In the last two months, however, he began to leave the house less often, at first staying home for two or three days at a time, then waiting up to a week or more before going out. Worried about how he was managing, Alan offered to arrange extra support through Meals on Wheels, Senior for Seniors or CCAC but his dad always refused. He said that if his dad’s mind was set against an idea, “there was nothing that could be done about it.” In fact, before his mother was placed at the LTCH, Alan had actually secured a double room for both

his parents at a Retirement Home located about 40 minutes outside the city but his father said no because he had his mind set on a specific facility in Hamilton. Alan acknowledged the challenge of trying to help his determined father, and felt frustrated that "the healthcare community looks at us like 'You're letting him live on his own?' … It's just like, 'What's wrong with you? What kind of son are you?'"

****** *Bob* ******

Bob had mostly positive things to say about the care he was receiving in hospital. "The nursing staff are really terrific, the way they can look after me, clean me up and all that, that's an embarrassing thing to me, my personal hygiene. I didn't think I could ever accept it, but I have to… I mean that's the last dignity gone." He said that the doctors were terrific too, good at listening to him. Although he had been moved to different rooms a number of times during his hospital stay, he said this did not bother him, though he wondered "Just what does the 'Flex' mean?", referring to the name of the ward he was staying on at the time.

At the second interview which occurred just after he was transferred to the Flex Ward, Bob commented that there wasn't much to tell since the previous interview, that he continued to spend most of his day in bed. He described going down to the dining room to have lunch and do crossword puzzles with a few other patients, activities which he enjoyed since they allowed him to mingle with other people. However, "when the session is over … there's not much." With a tone of resignation he said that "they try their damndest to entertain you but, it's a twenty-four-hour day here. [I'm] laying in bed … thinking of … the rest of my life." He was beginning to walk short distances with

assistance and a full standing height walker but said that he only walked "once a day, and not every day" and that what they did with him got lost on weekends because there was "no exercise at all."

Bob was very upset that he was not included in a crucial family meeting where it was decided that he would remain in hospital (rather than returning home) to await placement in a LTCH.

> P: How they can hold a meeting like that and not have the person you're talking about and discussing have an opinion? Doesn't make sense… The only family member excluded was me…
> I: Why do you think you were not included in that important meeting?
> P: I had no idea at all, why would she exclude me? …all I could say to them is I don't agree with certain things they're saying. They're afraid of what I'm going to say or they don't want to hear what I want to say.

****** *Alan* ******

Alan was upset about many experiences he had had since his father's hospitalization. At the beginning of the interview, he summarized his overall experience by emphasizing that "the degree of communication is terrible… It's rare that someone will come to me and say this is what's going on."

As an example, Alan was very concerned about testing that was done to assess whether his father had C. difficile. This was particularly upsetting for him because the local newspaper at that time was reporting frequently on an outbreak of C. difficile at the hospital.

> You know, I hear that they do this test and that test … putting him through all kinds of stress and strain. They do a C dif test and a week later I ask if there are any results and they say 'Oh there's no results yet.' I mean, come on, I'm not an idiot. A test like that

> they should have results back within hours I would assume… I finally saw a doctor the other day and he said, 'Oh that was negative, blah, blah, blah', but he's still in isolation … And then I heard it was E-coli and I said well where's this coming from?

Alan also described a dispute he was having with the hospital about the timing of the ALC co-payment. His concern was about the date being used to back date the start of the co-payments, a time when he felt that his father's situation was still very unstable, and certainly not a time when he was ready for transfer to home or LTCH. "I'm not disputing the co-payments, I'm disputing the timing of the co-payments."

Alan was also concerned about certain larger injustices he perceived about the whole policy of co-payment. He felt that the payment was unfair on at least three counts. First, the level of service provided at the hospital did not match that which would be available if his father were actually living in the LTCH. Second, the co-payments created exceptional financial burden for his parents because they were being paid while simultaneously carrying the expenses for the house, and his mother's LTCH placement. Third, in addition to the co-payment, the hospital levied charges for services like parking and television that would normally be included in the expenses at a LTCH. Altogether, Alan felt that the ALC co-payment and other charges levied by the hospital were unjust efforts to recapture expenses.

> What you are doing [is], 'Because he is in the hospital he is eligible to go, so let's strip him of every penny he has while he's in here.' And it just seems so callous and so cold.

Alan was passionate in advocating that his parents be reunited. As he put it, "It sounds melodramatic but he is going to die if they don't put them together. … his days are numbered, I understand that, he understands that but I just want him and my mom to

have some time, that's it." Given the length of time that he had been struggling to get his parents reunited, Alan was very well informed about the rules and regulations regarding the placement process for LTCHs in Ontario. In fact, just before the interview, he had taken the extraordinary step of approaching his Member of Provincial Parliament (MPP) about what he saw as a catch-22 preventing the reunification of his parents. He highlighted a process of "leap-frogging" whereby the stated priority of reuniting couples in the same LTCH is continually over-ridden by the priority to seek crisis placement for individual patients in the community and in the hospital. As he explained to the assistant to the MPP, "So unless all of a sudden there are no crisis people on that list they are going to keep jumping my dad and he'll never move in there. What are the odds?…This is a catch-22. And she said, 'Our hands are tied.'" Alan said that he was feeling "exasperation, it's gone beyond frustration" and summarized his concerns by stating, "If someone tells me one more time that that is the way the system works; the system is broken; it needs to be fixed."

****** *Bob* ******

About one week after the interview with Alan, I was surprised to hear that Bob had suddenly been offered a bed at the LTCH where his wife lived. I quickly arranged a third interview that took place on the Flex Ward two days before discharge. We did the interview in his room because he felt too weak to transfer out of bed that day. Despite his fatigue, it was not hard to sense the excitement he felt about his imminent reunion with his wife, and the pride he felt about his son's efforts to make that happen. He explained that his son "phoned the Member of Parliament … And he was saying, it wasn't too

much after he talked to [the MPP] that we got in there." Bob explained that the problem was that he would not be on the same unit as his wife and so they wouldn't even have the opportunity to eat together. He said, however, that his son "isn't finished yet… He's going to chase everybody and his brother over it." He said of Alan, "He's like his mother… Never wanted to get her on the wrong side."

At our first meeting, Bob was clear about his view of the future: he had none. Despite the promise of this much anticipated reunification with his wife, Bob's view of his future had not changed. In the second interview, he said that he'd "had eighty good years you know, and I've traveled the world, I've been a lot of places a lot of people never get. …. But I've done a lot, I've seen a lot, I've had a good life 'til they took my wife [to a LTCH]." Then everything changed for the worse, and "it all tumbled down. Everything I worked for all my life." As we spoke together at this last interview, Bob once again confirmed what he had consistently said throughout all the interviews.

> I don't have a future, the nursing home will be someplace to die. That's all it is and they make me fight to do that, at least, they make my son fight. If they can get me moving around like my wife is moving around maybe my attitude will change. I've been laying for two months – that's no good.

****** *Alan* ******

About a month after Bob's discharge I received an email message from Alan thanking me for doing the study. In that email, he reflected on the fact that the transfer to the LTCH was somewhat anticlimactic because his father's health was not what they had been hoping for going into the home. Four months later, I searched the obituaries in the local newspaper and discovered that Bob died about three weeks after that last email from

Alan. I was not surprised to hear this, but I was sad to know that in the end, Alan's father and mother had so little time together. This is not the ending any of us had been hoping for. It was the ending, it seems, Bob had expected.

The Story of Nancy and Barb: At My Age, What Is There to Hope For?

****** *Nancy* *******

Nancy (early 80s) was a tall woman with white hair, bright eyes and an alert, friendly manner. At the time of recruitment, her status under ALC designation was 'ALC - To Be Determined' meaning that it was not yet clear which of Retirement Home or LTCH was the more appropriate place of care. On the day of the first interview, I was surprised to discover that she had forgotten some of the details around the interviewing process that we had discussed the day before when we first met. Over the course of the interview, it became clear that she did have some form of cognitive impairment. For instance, her thought processes were quite scattered and disjointed, and she was vague whenever I pressed on details of things that she was telling me. However, I remained confident that she understood the purposes and implications of her participation in the research, and clearly she was highly motivated.

Nancy started the interview by describing the death of her husband, the owner of a drugstore, almost 30 years ago. After he died, there was "nothing doing you know, because your husband is gone." She managed to stay in the house because of her husband's insurance plan and hired someone to help with maintenance around the property. She valued relationships with her two daughters, and spoke warmly about the circle of female friends and neighbours that she would regularly visit. In recent years, it

was more difficult because these friends had aged and moved away, or were living in institutions with supportive care and were unable to visit. This resulted in feeling like she was no longer "known" by her new neighbours. "Everybody else has moved out and gone someplace else, so they don't even know me now … like nobody's got time for you [yeah] they really don't."

Just before coming to hospital, she said she wasn't taking very good care of her diabetes and had a number of episodes of passing out. On the day of her admission, she was lying on the chesterfield and somehow fell off. She could hear the phone ringing but couldn't get up to answer it and eventually her daughter came and found her on the floor and sent her to hospital.

****** *Barb* *******

Barb (age late 50s) was tall and slim, with short, brown hair. She spoke affectionately about her mother and explained that she had lived on her own at the house ever since Barb's father had died and for quite awhile had a good circle of friends. In recent years, however, Barb grew concerned that her mother was becoming more socially isolated as contacts with her aging friends diminished. Despite the increasing isolation, and increasing episodes of falling and other signs of physical decline, her mother stubbornly insisted on remaining in her own home. Barb and her sister had attempted to get Nancy to accept CCAC services but she always refused.

****** *Nancy* *******

Nancy said she didn't have much that was positive to say about her experience of being in the hospital. She complained that "it's boring and I mean I'm lying there all the

time… they get mad at me because I'm whining … but there's nothing else." In particular, she found the weekends very hard: "Have you ever been in the hospital Saturday and Sunday? It's pretty awful." Though more mobile than the other patients in the study, she was still unsteady on her feet, dependent for transfers, and requiring assistance and monitoring when walking. As a result, she was essentially confined to her room on weekends with little opportunity for activity except reading the newspapers and magazines which her daughter and some of the staff brought for her.

During the week, Nancy enjoyed spending time in the recreation room with a recreation therapist and other patients. They would read the newspaper, or do crosswords together, and although her "brain has gone partly there and partly some other place" so that she and some of the other patients struggled with the crosswords, she did enjoy being with other people. She also participated in an "exercise club" every day. However, she was in bed for the night by 6:00 pm and said she had a very difficult time sleeping, even though the staff thought she did sleep. "They come in and say you were sleeping all night. You're not sleeping, you're kind of in a doze."

Nancy was also upset about having to wait so often for the care that she needed, saying that sometimes she had to wait one to two hours for a response after ringing the call bell. She provided one example around waiting for assistance after toileting, a frequent concern for her given problems she was having at the time with her bowels. This particular episode appears to have occurred around the time of shift change on the ward.

> I have to ask when I want to go to the bathroom because my bowels are so bad I could fall and I try it and I do it, but if I ever fall I've got a problem, so you know. And you can sit there for an hour and a half you know. I like to go before a meal, but they go at seven.

> Once they put you there and they want to go home you know, I don't blame them really but I don't want to sit there for two hours.

Nancy felt she wasn't "known" by staff members at the hospital. She said there were many people coming in and out of her room and it was hard to know what each of their roles was and what their responsibilities were for her care. "They don't even know who I am you know… And those girls come in and they're doing their job and they don't have time to talk to you."

Nancy enjoyed getting to know her room mates but was frustrated because no one would stay there for very long. "They wouldn't last too long, maybe a couple of days. I don't know where they would move them." She described one day with three different roommates which was particularly distressing for her.

> I had this Italian lady, she was in the next bed, I went …to the bathroom and I came out and they said to me you've got a new partner, and I thought they were talking to her you know. They meant I had the new partner. And you know, I had three that day, they took her out.

Nancy was only informed on the very morning of her transfer from the Flex Ward to the ALC Ward that she would be moved within the hospital. She was urged to be ready at any time with all her things packed up and ready to go but ended up waiting all day for this transfer. "[It] went on and on and I can't do anything, everything is packed … I can't get anything. And you know what, nobody even bothers with you then, the other girls. I know they're busy but we'd like a little attention." Nancy was baffled about why she was being moved to another ward, saying they "never mentioned why they were moving me. Did I get better?" She also felt indignant that she was given so little warning and that she wasn't better informed about what to expect. "With old people, we should be told… I

mean, I could be one hundred and five [years old]… but you still want to know, like we're not all stupid."

****** *Barb* *******

Much of the first interview with Barb focused on a variety of concerns she had about how communication with her mother and her was handled during the hospital stay. "I think the information could have been explained a little more clearly because I don't, I don't understand the system that happens in here. I'm sure everyone is trying to do their best but maybe I just didn't know the right questions to ask." Communication ended up being much more difficult than she expected.

> My sister-in-law had gone through this situation several years ago and she said… 'Don't worry, they'll get a team together and sit down and have a family communication talk' … So that was in the back of my head. I'm thinking, not sure what hospital she went to but I didn't find it worked that way. [yeah] Um, I guess if, if someone could just sit down and just tell you what they are going to do.

The main challenge she faced was not understanding the way the placement process worked in her mother's situation. Particularly frustrating was the fact that the level of placement that her mother required was still undecided between Retirement Home or LTCH. "It's been somewhat um, frustrating because I don't know which road we are going down and … maybe …nobody does at the moment. So I've been trying to cover a lot of the bases … It's very time consuming." She explained that initially, she understood from the social worker that she should tour LTCHs as this would be the most appropriate level of care for her mother. Later, the social worker informed her that she

should rather be touring Retirement Home settings. Barb said that as a result of this miscommunication she ended up wasting a lot of time touring the wrong facilities.

Overall, the process of investigating placement options for her mother ended up being very time consuming, "just the running around or on the telephone with CCAC, … it's probably more the CCAC that I have complaints against because I haven't found them helpful at all." She explained that "I thought I could just call them and get them involved but it doesn't work that way… I thought the CCAC are here why can't they just go to her room and do the assessment?"

In the end, because CCAC did not do LTCH assessments in the hospital, Nancy was told she had to go to a Retirement Home in order to be further assessed and an application made for LTCH if that was eventually deemed to be necessary. Barb thought that it "would be hard on her [mother]… to move twice… I guess what I want is a clear answer and I'm not getting that." She concluded that it would have been very helpful if early in the ALC hospital stay she had been given an information package that included an overall description of the usual steps that a patient and family went through for the placement process.

Barb wasn't told about the option for patients to obtain day passes to leave the hospital. "I didn't even know about the day passes until… her roommate got a day pass and I thought, 'Oh I didn't know about that.' I thought you're in the hospital, you're in the hospital sort of thing." Barb was disappointed because this lack of information coupled with the time she wasted touring LTCHs resulted in her mother not having the opportunity to visit more than one Retirement Home.

Given the fact that the level of placement was still to be determined, Barb was also concerned that her mother was not receiving more intensive opportunities for physical rehabilitation. “Why isn’t she in rehab rather than just being here [on the Flex Ward]? … She gets fifteen minutes [of exercise] a day if that, or ten, I don’t know.” Like her mother, Barb was also puzzled about what it meant when Nancy was moved within the hospital. “When she gets moved from the seventh [Flex Ward] to the second floor [Ward ALC], now they did say this was long-term care but I didn’t know if long-term care was actually better than the Flex or that’s oh she is sliding back down again?”

****** *Nancy* *******

The second interview with Nancy occurred on the ALC Ward on Sunday, two days after she was transferred from the Flex Ward. Nancy was preparing to travel the next day with her daughters to tour a prospective Retirement Home. She felt strongly about having an opportunity to review more than one Retirement Home. As she said, “I don’t want the first one ... if I have to spend the rest of my life someplace.” Unfortunately, given the circumstances described by Barb above, she had time to tour only one facility. Once the tour was completed the next day, a decision was quickly made to have her discharge to this facility by Thursday.

As Nancy reflected about the prospect of a move to Retirement Home, she had a number of questions. For instance, she wondered what kind of services the Retirement Home would provide.

> P: I got ten this morning, pills. When I get home [to the Retirement Home], well that’s going to be my home… are they going to take me off? …[And] when I get someplace do you think

> my, well I'm going to have to check my sugar but is it every day like I have done? …
> I: And so are you wondering, at the place where you are going whether they will help you with those things?
> P: Yeah, that's what I'm wondering.

Nancy also expressed great frustration with the lack of information she had received about her medical condition in anticipation of this move. She had a number of concerns which she felt a doctor should address including a recent rash. "That's another problem as they are moving from here to there …yesterday they said, 'Now three doctors will come in and assess you.' Never saw a doctor, sorry… I thought, I'm going out of here and nobody has assessed me." Regarding her view of the Retirement Home, she said "Like, I'm just putting in time, doesn't bother me going anywhere else, but it's going to be the same old thing you know. It's not your house." When asked about her hopes for the future, Nancy said "At my age, what is there to hope for?"

Despite obvious cognitive challenges, Nancy enthusiastically embraced the underlying purpose of the research project throughout the interviews. As she said at the first interview, "Somebody's got to do something about this healthcare for older people."

****** *Barb* *******

Barb and I met for the last time at a coffee shop at the main entrance to the hospital on Thursday morning as she was arriving to transport her mother to the Retirement Home on the day of discharge. She said that the move to the Retirement Home was going to be a big change for her mother but she was hopeful that the social interaction offered there would be a very positive thing. Barb mused that if her mother had only made a move five or ten years before, "it wouldn't be such a desperate move

now." She concluded by commenting that "My mom keeps saying, 'Well, what are you going to do about these old people?' I'd be curious to know the same thing."

Afterward, we walked over to the ALC Ward together and with a bit of a nervous chuckle she warned me that her mother was "on a protest" that day because she wanted to see a doctor before leaving the hospital and might not be dressed or ready to go yet even though the time to leave had arrived. Fortunately, we found her dressed and ready. We said a brief good-bye in the bedroom as Nancy prepared to leave with Barb, her personal items all packed and bagged on the bed and chairs around her.

The Story of Frank: I Just Take Things as They Come and Roll With the Punches

****** *Frank* *******

Frank (age mid 80s) was a tall man of few words. His recruiter had told me that he and his wife were both in the hospital at the same time and awaiting crisis placement in the same LTCH. His wife had advanced dementia. For my first contact with Frank, as instructed by the sign on the wall, I donned a gown and gloves to maintain contact precautions before entering his room. He had just completed treatment for C. difficile and the precautions were cancelled a day or two following this visit. The room was quite dark and there was only one bed located at the far side near the window. I found him lying quietly on his right side, awake and facing the window. After I briefly explained the study, he said he was willing to participate and we agreed to have an interview in the next few days. He was quite frail and tired, and said that his ability to participate would depend on how well he was feeling on a given day.

That Friday, I was surprised to hear that Frank had just received an offer for a LTCH bed for early the next week, likely Tuesday. Later that afternoon, I walked into his room, again finding him wide awake and lying on his right side facing the window. He recalled that I was the fellow from the University and when I asked if he would be willing to interview that evening, he said, “Sure.” I assisted Frank to a sitting position and helped him put on his glasses.

The most striking feature of the interview was the brevity and slow pacing of his responses to the questions. The entire interview lasted only 37 minutes, and a significant amount of this time was occupied by silence as I waited for his responses. Another overall feature of the interview was the relative lack of emotion expressed by Frank. I was very aware of the difficult situation that Frank and his wife were in, yet his manner in the interview didn’t seem to reflect much distress.

Frank described growing up in a neighbourhood just east of the downtown. He said he worked in the retail food industry. “I got to know a lot of people… But I always tried to, uh, get along with people. Sometimes it’s not always easy, but you do the best you can with whatcha got.” In recent years, since retiring, he said he liked to go regularly to the Tim Horton’s and read the newspaper.

Just before coming to hospital, Frank was living with his wife in an apartment building. Things weren’t going too badly until he fell while trying to put his pants on. He injured his shoulder and as a result had more trouble doing things around the home. At that time, a paid caregiver from CCAC was sent to help out his wife. “She’s eighty-five

or eighty-six and they had to make the odd meal and stuff. *[Yeah.]* She needs some help."

Frank explained that his wife was also in the hospital because her back had been giving her trouble. She came down in a wheelchair with his son to visit him one day less than a week before. She said she was not doing too badly. Although he was hopeful they could eventually put the two of them together in the same room, he felt good just knowing they were in the same building.

Frank had no complaints about his experiences in hospital. He felt they were doing everything they could for him, providing food, and helping him to go to the bathroom. He said he had to wait sometimes after ringing the call bell but "Eventually they come. *[Yeah]* If they don't then I call them again. *[Yeah]* But as a rule they're not bad." He said they were helping him to walk every other day with the walker until he got tired. He commented that "In the old days I, I never got tired." He said that being in the hospital room by himself all day didn't bother him at all.

Overall, he said he felt safe in the hospital, and that was the most important thing.

> I: What is good about your experience being in hospital here?
> What's good about it?
> P: Well, feel safe. [Yeah.] And it's protected.
> I: Protected?
> P: Yeah and uh you have hospital staff here if you need it. [Yeah.]
> You can't ask for much more.

Frank explained that the plan was for his wife and him was to go to a LTCH together. He said he'd seen a list and there were two or three they were deciding between. He had no idea how long the wait might be.

Frank said he wasn't worried about anything.

> I don't know. I never really worried about anything my whole life… I just take things as they come [right] and roll with the punches. Not a lot you can do. [Yeah, yeah.] If you get upset about everything that goes wrong, you're always upset... If you don't, you're always in conflict… with yourself.

About the future, Frank acknowledged that for now he and his wife would need to be in a LTCH but said he wanted to get his health back and hoped to be able to return to living with his wife at their apartment.

> I hope to get my health back. *[Yeah?]* And my wife's pretty healthy, she's not too bad. Maybe we can get along when we're home. *[Mhm.]* I think… *[Yeah?]* They could still have a caregiver come once a week and… I think that can be arranged. *[Mhm.]*And that way there's somebody there to oversee things.

Although I had some contact with his daughter about participating as a family caregiver in the study, in the end, she declined to do so.

Frank had been scheduled to be discharged to the LTCH on Tuesday following that first interview. On Monday, I had been intending to approach him for a review of the story summary but was disappointed to learn that afternoon that he had been discharged earlier that day. When I commented about how quickly this discharge had occurred relative to others on the study, the recruiter explained that Frank had likely been accepted so quickly because he had picked as his top choice a LTCH in the downtown area of the city that had a relatively poor reputation and resultant short waiting list. She said that he did this because his wife had previously applied to this same LTCH while still living in the community and had picked it as her top choice because she had a friend who worked there. She didn't think it would be long before his wife would also be offered a bed.

CHAPTER 5: FINDINGS - THEMES ACROSS STORIES

Introduction

This second findings chapter presents the themes about the ALC experience that were identified across participant stories. The overall theme was uncertainty. Participants spoke about experiences of uncertainty in a number of different realms that reflect the dimensions of experience described by Clandinin and Connelly (2000), that is, time (past, present, future), place or a series of places, and personal and social aspects of interactions. In the dimension of interpersonal interactions, participants spoke of being uncertain about how basic processes relevant to their hospital stay worked. In the dimension of time and place, they described various experiences related to uncertainty about when events relevant to their care at the hospital would happen. Finally, in the dimension of personal self knowledge, they spoke about uncertainty regarding their understanding of themselves in light of the circumstances surrounding their initial hospitalization and time of stay under the designation of ALC.

The overall theme was composed of three main themes and twelve corresponding sub-themes, listed in Table 1. The main themes included: (a) I don't know; (b) waiting; and (c) I never thought I'd end up my life like this. Each theme is described in detail, with relevant sub-themes and supporting quotations, in the following sections.

Table 1 - Themes Across Narratives

I Don't Know

- I don't know… the right questions to ask: Problems with communication
- I don't know… about hospital processes
- I don't know… about the placement process
- I don't know… about medical assessment, diagnosis, and prognosis

Waiting

- Waiting to be more mobile
- Longing for meaningful activity
- Waiting for care
- Waiting for placement
- Waiting for couple reunification

I Never Thought I'd End Up My Life Like This

- The past: "I was on the go all the time"
- The present: "I never thought I'd end up my life like this"
- The future: "At my age, what is there to hope for?"

I Don't Know

All participants identified concerns about important information they did not receive related to the patient's hospitalization and planning for discharge. The phrase "I don't know…" was used frequently by several patients and caregivers. The sub-themes are: (a) I don't know the right questions to ask - problems with communication; (b) I don't know about hospital processes; (c) I don't know about the placement process; and (d) I don't know about medical assessment, diagnosis, and prognosis.

(A) I Don't Know… the Right Questions To Ask: Problems With Communication

Several participants identified concerns related to problems with poor communication they experienced during hospitalization, between staff and patients, staff and caregivers, and between staff. Some of these observations were quite insightful, informed as they were by prior personal or work related experience.

Barb emphasized the challenge she faced in trying to figure out how to get the information she needed to guide effective planning and decision-making for her mother's care. She commented that "I think the information could have been explained a little more clearly because I don't, I don't understand the system that happens in here. I'm sure everyone is trying to do their best but maybe *I just didn't know the right questions to ask [italics added].*" Barb emphasized the importance of structured processes of communication on the part of hospital staff because her own lack of familiarity with aspects of hospital care and the process of planning for placement left her feeling overwhelmed, not even knowing 'the right questions to ask' on behalf of her mother. She also described the experience of her sister-in-law who said "'Don't worry, they'll get a

team together and sit down and have a family communication talk'" and lamented that in the end she "didn't find it worked that way" and that communication was much more difficult than she had expected.

Alan was passionate in his criticism of the many communication problems he had experienced during his father's hospitalization, noting that "the degree of communication is terrible… It's rare that someone will come to me and say this is what's going on." Overall, he felt there was a problem with the way that communication was coordinated at the hospital.

> There seems to be a distinct lack of communication between the staff and the patients, the staff and each other… I work with clients and … if I had communication like this I wouldn't have a job. It's terrible … it seems unprofessional and it makes me wonder, I mean, not the abilities, but like the coordination.

Although less frequently, patient participants also commented about problems with communication. Teresa was disappointed when she was told by staff members at the nursing station that they didn't know the schedule for Mass at the hospital. She responded by asking, "Well, aren't you an information centre?' and they said, 'No, we're a nursing station.'"

B) I Don't Know … About Hospital Processes

Participants described not knowing about important basic processes of care during the hospital stay while designated as requiring ALC. This lack of information included not knowing the meaning of important words and phrases, not knowing the roles of different staff members, finding the processes of patient isolation unclear, not knowing about day passes, and not knowing why the patient was being moved.

Participants did not know the meaning of important words and phrases used at the hospital. None of the patient participants recognized or knew the meaning of the term 'Alternate Level of Care.' Although the family caregivers were generally more aware of the term, Sarah did not know what it meant. "Nobody has explained to me what alternate care is. Really, what is alternate care? Nobody has ever explained that to me." Several participants wondered about the meaning of the names of different wards in the hospital. For instance, while he was staying on the 'Flex Ward', Bob said,

> Just what does the 'Flex' mean?... I asked the doctor the same thing, couldn't get an answer … it's strange. I thought it was maybe like rehabilitation, but it's not. Flex. I guess my next step will be rehabilitation.

Teresa commented that she had trouble discerning the different roles of staff members at the hospital and so was unsure about who did what job, and who to ask for information: "When people come in they just say, they don't even say who they are so I don't know who they're connected with."

Alan was frustrated about the lack of clarity around processes related to patient isolation for his father.

> When they moved him back over to cardiology and then he was in isolation because, because that other nurse said something. I'm going. 'are you kidding me? Because somebody over there said something, you don't know why he's still in isolation?' … there should be better signage or something like that saying isolation, … I think that's insufficient.

Barb lamented the fact that she wasn't told about the option for patients to obtain day passes to leave the hospital nor the availability of wheelchairs to assist transport via car. She said, "I saw … the wheelchairs at the front main entrance [yeah] I just thought I'm going to use that to pick her up. Nobody tells you this though." This lack of

information was significant because her mother would have been functionally able to use a day pass and could have toured prospective Retirement Homes as she clearly wished to do and in the end did not have time.

Patients and family caregivers were puzzled about moves that happened within the hospital, and tried to read meaning into the moves without the benefit of direct explanation from members of their health care team. When her mother had previously been in a different hospital, Sarah had observed unexpected and frequent moves that occur in hospital and had labeled this phenomenon "musical beds."

> I'd like to know more what's going on with my father … like he was up there … the next thing I know, he's down here [ALC Ward] and they didn't even explain to us… like, what the hell's going on? … and then I thought they were going to start those musical beds again like they generally do.

Nancy wondered why she was moved from the Flex Ward to the ALC Ward: "She never mentioned why they were moving me. Did I get better?" She went on to lament that "With old people, we should be told… I mean, I could be one hundred and five [years old]… but you still want to know, like we're not all stupid."

Her daughter was just as puzzled about what it meant that her mother was moved: "When she gets moved from the seventh [Flex Ward] to the second floor [ALC Ward], now they did say this was long-term care but I didn't know if long-term care was actually better than the Flex or that's oh she is sliding back down again?" Barb reflected more generally on the puzzling series of moves that her mother had undergone during her hospital stay.

> P: I'm just kind of curious why she got moved around the beds. I think I understand the move from fourth floor to here [Flex Ward] because the fourth floor did require a little more care. But she was moved twice there and I

> wondered why they moved her … 'She's being moved to flex' … doesn't mean anything to me.
> I: So it would help you to understand why, what's the reason for movement?
> P: Well they did say that's a good thing … I said, at least you are moving up in the world, four to seven. But … people just assume you know the information… So I probably just assumed certain things and I should have just asked, but who do you ask?

Even at discharge, some participants did not know why they were being moved. On the day she was being moved to the Assess and Restore program at St. Joseph's Villa, Teresa did not understand why she was being moved and speculated "they must think there is some room for improvement otherwise they would leave me here. But no one has said."

C) I Don't Know … About the Placement Process

In the midst of the experience, participants had many unanswered questions about the process of arranging a placement in a Retirement Home or LTCH. These questions lingered sometimes right up to the moment of discharge. For instance, at the second interview a few days before discharge, Janice said about her understanding of the placement process "Well they haven't approached us, so I'm surmising that she must reach a level of care or there must be vacancies available for her to go to." Overall, participants expressed not knowing about financial aspects of the placement process, not knowing basic information about the characteristics and services of Retirement Homes and LTCHs, not understanding the overall process for arranging placement including the role of the CCAC, in particular in the case where there is uncertainty about which level of placement is most appropriate to meet the patient's needs, and finally, not knowing

about crucial aspects of the plan of care for placement and feeling frustrated about not being included in processes of planning and decision-making leading to these plans.

A number of participants were concerned about finances and had misunderstandings about this. Dan for instance said "I worry about my house and my belongings. Well they are all gone now from what I hear, it's been stripped." Barb was concerned that "in the case of Retirement Home ah, you have to put down a deposit or you have to do this, this and this, so there's banking issues … Again, it's just that no one has said we're going to do this."

Participants identified that they did not know basic information about the characteristics and services of Retirement Homes and LTCHs. On the day of discharge, after eight and a half weeks under ALC designation, Teresa said "I don't know, what's the difference between a LTCH and a Retirement Home? So I'm hoping that that will sort itself out." At the second interview a few days before transfer, Nancy wondered about what kind of support services she would receive at the Retirement Home, wondering if they would take care of her medications, monitor her blood sugar, and so forth. Nancy's daughter was also unsure about the level of service that would be available at either Retirement Home or LTCH, and said she did not understand what level of patient function was appropriate for each setting.

One of the problems that both Teresa and Nancy faced was uncertainty about what level of placement was appropriate, whether Retirement Home or LTCH. For Teresa, this meant eventual transfer to the Assess and Restore program in another institution for further assessment. Barb described the problem for Nancy this way:

> P: It's been somewhat um, frustrating because I don't know which road we are going down and … maybe …nobody does at the moment. So I've been trying to cover a lot of the bases for the, the alternate care…so it's, it's very time consuming.
> I: When you say which road, what, what are the roads?
> P: Well I think there's only Retirement Home or long-term care and at the moment I don't think she's one hundred percent able to look after herself completely so Retirement Home doesn't quite fit. But for the long-term care, the CCAC has to do an assessment and they haven't done that.

In this case, Barb pointed out that CCAC did not do LTCH assessments in the hospital so Nancy had to go to a Retirement Home in order to be further assessed and an application made for LTCH if that was eventually deemed to be necessary. When asked how she felt about her mother having to be transferred to the Retirement Home for further assessment, she replied, "I think it would be hard on her … to move twice. … I guess what I want is a clear answer and I'm not getting that."

Having become resigned to the need for transfer to Retirement Home for further assessment, Barb went on to point out that it would have been helpful to have known more about what process to expect when a patient's functional status is still unclear and determination of level of care would require a longer period of assessment.

> I guess it probably could have been um, stated that, okay we don't know, and in this application it's probably best to look at both the alternatives. Um, and then you know I wouldn't have been kind of focusing on one and not the other.

Barb went on to explain that initially, she understood from the social worker that she should tour LTCHs as this would be the most appropriate level of care for her mother. The social worker later informed her that she should rather be touring Retirement Home settings. Barb said that as a result of this miscommunication she ended up wasting a lot of time touring the wrong facilities. Overall, the process of investigating placement

options for her mother ended up being very time consuming, "just the running around or on the telephone with CCAC, … it's probably more the CCAC that I have complaints against because I haven't found them helpful at all." She expressed frustration with the overall process around waiting lists for placements and the role of the CCAC in the placement process saying, "I was getting misinformation also from the CCAC" and worried that her mother was "losing time because she… could have been on a waiting list." She concluded that it would have been very helpful if early in the ALC hospital stay she had been given an information package that included an overall description of the usual steps that a patient and family went through for the placement process.

Patients and family caregivers in this study talked about not being included in the processes of planning and decision making for placement while the patient was designated as requiring ALC. During the fourth interview with Teresa, about three hours before she was discharged from hospital, I asked what was happening that day. Teresa responded with a long list of the things that she didn't know about concerning the Assess and Restore Program that she was about to enter. When I asked if she had any idea what the plan was, she said, "Not a whit."

Bob was very upset about the fact that he was not included in a crucial family meeting where it was decided that he would remain in hospital (rather than returning home) to await placement in a LTCH. Incredulous, he commented, "How they can hold a meeting like that and not have the person you're talking about and discussing have an opinion? Doesn't make sense."

Nancy felt strongly about having an opportunity to review more than one Retirement Home. As she said, “I don’t want the first one ... if I have to spend the rest of my life someplace.” Unfortunately, she ended up only having time to tour one facility. As Barb later explained, it was the lack of information about the option of a day pass and the miscommunications mentioned above around which facilities to tour that contributed to this outcome.

D) I Don’t Know … About Medical Assessment, Diagnosis, and Prognosis

The third area where patient and family caregivers felt they were not provided important information in a timely way was medical information related to assessment, diagnosis and prognosis. Specifically, participants expressed concern that they did not know about medical assessments such as the results of lab tests, they did not receive adequate diagnostic and prognostic information concerning the illness that brought them to hospital, and they did not receive clinical assessment of recent physical concerns.

Alan was very concerned about communication regarding the results of tests and investigations that had been done for his father. A specific example he spoke about was a test done to assess whether his father had C. difficile. This was particularly upsetting for him because the local newspaper at that time was reporting frequently on an outbreak of C. difficile at the hospital. He wondered why they were “putting him through all kinds of stress and strain” to do tests yet not following through in providing results in a timely way. He was told a week after the C. difficile test, “Oh there’s no results yet” only to find out some time after that his father never had C. difficile in the first place.

Several participants were concerned that they still did not know enough about the illness that brought them to hospital in the first place. Dan complained that, "They haven't even looked at my feet. … what I come here for is the feet." His daughter in turn was concerned that she first found out through "strangers" about the fact that Dan had been diagnosed with pneumonia. "I just wish they would notify me more about what's going on… I didn't even know that he had pneumonia… that's partly what I'm frustrated about."

Like Dan, Teresa had questions about aspects of the illness that brought her to hospital. At the first interview, she wondered about the prognosis of her medical condition. She said that it was getting more difficult for her to walk and tried to rationalize why this wasn't explained directly to her. "But whether people are afraid to tell you deliberately because of your reaction or because they think they're helping you by not providing you with this information, I don't know." At the time of discharge, she still had ongoing questions about her medical condition and wondered whether the problem with not being able to use her hands was related to this.

A few days before her transfer to a Retirement Home, Nancy expressed great frustration with the lack of information received about her medical condition in anticipation of this move. She had a number of concerns which she felt a doctor should address including a recent rash.

> That's another problem as they are moving from here to there …yesterday they said now three doctors will come in and assess you, never saw a doctor, sorry… I thought, I'm going out of here and nobody has assessed me.

On the day of her mother's transfer, Barb explained to me that her mother felt so strongly about this issue that she had been holding a 'protest' all morning, refusing to get dressed until a doctor came to assess her! Although no doctor ever came to see her, she did not in the end hold up the discharge as her daughter had feared. Barb commented more generally about the problem with communication around assessments: "I don't know if assessments were ever done. Well I do know one was done but you don't know when, where, what are the results? What do they say? What does that mean?"

Waiting

A second main theme that was identified across participant stories related to the idea of 'waiting.' This theme was expressed in a variety of ways by both patients and family caregivers, but the unifying idea was their description of the experience of what it was like to wait while time passed in anticipation of some future event or activity. The feelings associated with this experience ranged from resignation to the inevitability of waiting, to frustration and exasperation which found expression in self-described whining and complaining among some patients, and strong advocacy on the part of some family caregivers to speed up the process. The specific subthemes were: (a) waiting to be more mobile, (b) longing for meaningful activity, (c) waiting for care, (d) waiting for placement, and (e) waiting for couple reunification.

A) Waiting to be More Mobile

All of the patients expressed a desire to be more mobile. This theme was expressed in a variety of ways including wanting to receive more assistance with exercise

and physiotherapy as well as a general desire to find compensatory strategies to be more mobile or active.

Several participants said they were waiting for more assistance to help them start walking. Dan said, "The doctor's not listening here. I came here for my legs to walk, they're puttering around with my bladder." He was quite disappointed because he said "I don't walk … not at all. I just lay in the bed and they use that hoist thing and lift me up and put me in the wheelchair." He said he did not receive assistance to meet this goal.

> I: Did they do exercise or physio earlier, earlier in the hospital? …
> P: No, no exercise … Vegetable, that's what they would call it, he's a vegetable if a person just laid there and don't do nothing.

Dan's daughter felt very disappointed about the lack of attention paid to her father's walking throughout his stay while under ALC designation and having seen the remarkable improvement in her mother's mobility after three months in the LTCH, felt that once her father was finally transferred, "the nursing home will probably have my dad up more going than the hospital."

Teresa also commented about the lack of opportunities to exercise:

> Here I'm not getting any exercise…. I know walking around will get my muscles going because you get, if you don't use your legs, the muscles in the back of your legs get flabby … you're kind of wasting away.

In the second interview, Teresa commented about sitting in the activity room in a wheelchair that she was unable to move herself because of weakness in her arms and hands.

> I would rather somebody walk me up and down the aisle than just sit there, at least you could see something going on, … but I realize you know, they don't have staff for all of this and I don't know how much volunteer staff they have.

Most participants lamented the absence of support for exercise or walking on the weekends. As Bob said,

> I: Have they been helping you to walk very much?
> P: No, once a day, and not every day, yet what they do gets lost in the weekends, no exercise at all.

Barb was concerned that her mother, who was receiving regular exercise, was not receiving more intensive opportunities for physical rehabilitation. “Why isn’t she in rehab rather than just being here? … She gets fifteen minutes a day if that, or ten, I don’t know.” This was a significant issue for her mother because her functional status was still under assessment as to whether Retirement Home or LTCH was more suited for her placement.

This desire for more mobility is linked to the other sub-themes in this theme. Because of lack of mobility, patients felt less able to access activities at the hospital that might have been more meaningful for them, and they noted that their dependence on others created the circumstances that lead to the experience of waiting for so many aspects of care. For many of the participants, it was the loss of mobility that was named (rather than their medical diagnosis) as the reason for their hospitalization in the first place and the cause of their need for placement in Retirement Home or LTCH.

B) Longing for Meaningful Activity

Patient participants described the challenges they faced related to the experience of waiting for time to pass during their hospital stay. They seemed to attribute this experience to a lack of meaningful activity in which to participate and commented on

feelings associated with this experience including resignation and frustration which led to complaining.

Teresa complained about numerous aspects of her experience during the second interview. She said she had never before seen herself as a complainer and attributed this development to "the inactivity: … when… you have nothing else to do, your thoughts are all on you." She used the metaphor of "this beautiful clock on the wall" to eloquently convey the struggle she was experiencing with the slow passage of time on the ALC Ward.

Bob noted a similar sense of resignation "They try their damndest to entertain you but, it's a twenty-four-hour day here. You're laying in bed here, I'm not thinking of the future, I'm thinking of my entire life, you know, the rest of my life."

Nancy, like Teresa, described herself as "whining" because of the inactivity "it's boring and I mean I'm lying there all the time… they get mad at me because I'm whining … but there's nothing else." In particular, she found the weekends very hard: "Have you ever been in the hospital Saturday and Sunday? It's pretty awful." Her daughter explained that Nancy was stressed about this because "it's just dead on the weekends." Nancy, though more mobile than the other patients in the study, was still unsteady on her feet, dependent for transfers, and requiring assistance and monitoring when walking. As a result, she was essentially confined to her room on weekends with little opportunity for activity except reading the newspapers and magazines which her daughter and some staff brought for her.

Patient participants commented about specific activities that they engaged in during the daytime. Bob enjoyed the crosswords he did with a recreation therapist and several patients in the activity room on the Flex Ward, but "when the session is over … there's not much." As a former taxi driver, he had always enjoyed talking to people and found the social aspect of being with others as meaningful as the activity itself. Unfortunately, Bob was dependent for all transfers and mobility and said that he spent most of the rest of his time lying in bed.

Although earlier in his stay on the ALC Ward Dan had joined in on planned activities in the family room, he explained in the first interview that he no longer felt comfortable going there "because all these weirdoes are down there and they don't do nothing, they just sit there and stare at yah." As a result of this, and the fact that he was completely dependent for all transfers and unable to move his wheelchair by himself, he spent almost all of his days in his bedroom, and most of this time in his bed. "Not much to tell, I go to sleep, lay in bed all day." He said he might have enjoyed playing cards with someone in his bedroom but felt that that would not work out because he was certain that one of the wandering patients would come and disrupt the game. In the second interview, Teresa commented about the activities in the dining room on the ALC Ward "they'll have crafts, pottery that I am not interested in."

A striking exception to this general pattern of lack of meaningful activity was described by Teresa nine weeks after she was designated ALC. Mostly as a result of her own initiative, she was able to mobilize her wheelchair by herself up and down the halls. After discovering the possibility from a priest that was visiting her at the time, Teresa

wheeled herself down to the nursing station and doggedly pursued making arrangements to attend Mass in the chapel at the hospital. At the third interview several days after this experience, Teresa proclaimed excitedly that she finally "got to Mass … And ah the Priest, a young Priest, I don't know who he is but he gave a lovely Homily, so it was really delightful, it was so long since I've been to Mass, … it was really good." In fact, the entire tone of this interview was strikingly more positive than the previous 'complaining' interview and it was not difficult to imagine that the presence of this very meaningful activity in her life had helped to shape that tone.

C) Waiting for Care

In addition to waiting for more mobility and more meaningful activity, participants waited for assistance with activities of daily living like eating and personal care. At times, this wait could extend for very long periods of time.

Teresa, at a time when she was still dependent on staff for most Activity of Daily Living (ADL), spoke about waiting to be transferred back to bed, waiting for assistance with her meals, and waiting to toilet:

> When you get tired and you want to go back to your room, they take you in the wheelchair and then you have to wait for somebody to put you to bed … The same as when they serve you the meals … somebody in white will bring in the meal and … if you need help, you have to ring for somebody else and they will come in. ... if I want to go to the bathroom …if they don't come right away and I have to call two or three times … I try and give enough notice so that I don't have an accident.

In observing other patients on the ALC Ward who were more functionally impaired than she was, in terms of physical mobility and cognition, Teresa commented that the degree of waiting seemed to increase with the degree of disability, saying "Like

if you're the more disabled to me you always have to wait till everybody is looked after." She acknowledged the challenges staff faced but still wished "people could be more helpful to them."

Nancy said that one time while toileting she had to "sit there for an hour and a half" waiting for help after ringing the call bell. This example appears to have occurred around the time of shift change on the ward. She said she didn't want to blame staff for delays like this but emphasized how hard she found it to wait so long.

On the morning of her transfer from the Flex Ward to the ALC Ward, Nancy was urged to be ready to transfer at any time with all her things packed up and ready to go. She said she waited all day for this transfer:

> [It] went on and on and I can't do anything, everything is packed, … I can't get anything. And you know what, nobody even bothers with you then, the other girls, I know they're busy but we'd like a little attention.

D) Waiting for Placement.

Although the patients expressed frustration about their present circumstances and were all anxious for varied reasons to move on from the hospital, family caregivers were particularly expressive of their frustration and concerns for the patient and the circumstance of protracted waiting for transfer to the alternate place of care. This frustration led to strong action in some cases, and led to feelings of resignation in others. A particularly contentious aspect of waiting for placement was the experience of ALC co-payments which will be described in some detail.

Fed up with the length of time she and her father had been waiting for placement at the LTCH, Sarah described the moment that crystallized her efforts to advocate on behalf of her father to speed up the placement process.

> Well last week I was, I came back from the trip and I said enough is enough. I've waited two months, they've done, I feel they've done nothing for him. They've done nothing at all. And I feel, I don't know what was going on behind the scenes but to me I felt it wasn't moving fast enough.

She called the LTCH to ask why there was such a delay in the placement. She then phoned the CCAC and "spoke sternly" saying she wanted the placement to happen as soon as possible. She was surprised to get a call four days later saying that her dad was being transferred to the LTCH the next day at 10:30am. In a similar way, Alan advocated tirelessly to have his father transferred to the LTCH. His efforts to reunite his father with his mother will be described in greater detail in the next section. In the first interview, Barb said with resignation about her mother's situation that "I've kind of given up on asking like when she's getting out because… no one seems to know."

During this period of waiting for placement, all patient participants were required by policy to start making ALC co-payments to the hospital. Two of the four family caregivers spoke strongly about their concerns about these co-payments. In the first interview, Sarah commented that she thought her father would receive better physiotherapy service at the LTCH than he was in hospital, and described her reaction to the information about the co-payments.

> I was dumbfounded about how, they're supposed to be a service for the patient … I totally get that they've got to make their money. But ….five thousand dollars for twenty-six days … my dad's insurance companies are questioning it too … But I'm sitting here thinking, oh, I'm ready to pull my dad and take him home if I

> could, … till a place came available with my mom. But then, then I'd probably never get him out.

At the time of the interview with Alan, he was in the midst of a heated dispute with the hospital about the timing of the ALC co-payment. His concern was about the date being used to back date the start of the co-payments, a time when he felt that his father's situation was still very unstable, and certainly not a time when he was ready for transfer to home or LTCH. As well, even if his father had been well enough to go home to wait without co-payment fee for placement as encouraged by the province's Home First initiative, he had just been told by CCAC that they would not be able to provide sufficient support services in the home for his father. This same information was also being reported in the local newspaper at that time. Alan said

> P: I'm not disputing the co-payments, I'm disputing the timing of the co-payments … He can't go home because he's too sick, not because he's waiting to go into a [LTCH as previously applied to in the community] home, they are coincidental.

Alan was also concerned about certain larger injustices he perceived about the whole policy of co-payment. First, like Sarah, he felt that the payment was unfair since the level of service provided at the hospital did not match that which would be available if his father were actually living in the LTCH.

> Somebody who worked fifty to seventy years and you know, accumulate this and have it depleted while he was away in the hospital. If he was in a [nursing] home and she's in a [nursing] home, you know, what I mean, what they have coming in will more or less cover it. … but I want it to go for life, not for existence… He's breathing, body is circulating, he's existing, he's not living and he is so depressed.

Alan pointed out the financial problems the co-payment caused his parents. Although the plan was for his father to transfer to LTCH, until that actually occurred, it

did not make sense to sell his parent's house. As a result, they were simultaneously carrying the house and it's expenses, the cost for his mother's LTCH placement, and the ALC co-payment. From Alan's perspective, this was a disappointing and unjust attempt by the hospital to recapture its expenses: "'Because he is in the hospital he is eligible to go, so let's strip him of every penny he has while he's in here.' And it just seems so callous and so cold."

Finally, despite the co-payment, the hospital also levied additional charges on the patient for services such as parking and television that he understood would normally be included in the expenses at the LTCH. As Alan stated it,

> You're raking people for the TVs in this place and for the parking, that is just, that is objectionable… I mean if you are lucky enough to get a spot, it's costing me seventeen bucks a day to come visit him and I think that's unacceptable. And then you know, the TV is eight dollars a day and half the time he can't see it because they come and see him and they turn the TV away so half the time he can't even watch it but he's paying for it. Oh but he can pay co-payments, just like he's at the home… And you know, I mean I make good money so I'm not in the same boat as other people, but I think it's just, it's not fricking right.

E) Waiting for Couple Reunification

Of the five cases followed for this study, three described situations where patient participants were separated for a period of time from their spouse while waiting for placement arrangements that would allow them to be reunited. For two of the patients, Dan and Bob, this time of waiting for reunification was quite lengthy and difficult, and for the third patient, Frank, this reunification happened in a relatively short period of time. This subtheme highlights the distress that this time of waiting for reunification caused the patients and their family caregivers, and sheds some light on the challenges and barriers related to achieving this reunification.

In all three cases, the patient's spouse had a diagnosis of fairly advanced dementia. For Dan and Frank, the couple had been living together in their own home just prior to this hospitalization. As Sarah, who lived with her parents, described it

> They were working like a little team there so then, and my dad was always watching her, he always made sure she was okay. And sometimes when he needed her for her hands and that then she would [help him].

In the case of both Dan and Frank, the illness, hospitalization and overall physical decline of the patient triggered a crisis which resulted in both the patient and their spouse requiring placement in a LTCH. In the case of Bob, this same sort of crisis had occurred about 18 months prior to this hospitalization. Alan described the circumstances leading up to his mother's placement in LTCH at that time.

> The one year my dad was in and out of … the hospital, about every six weeks. … So mom's home alone, she's got dementia, she can't look after herself so she was the primary, she had to go somewhere first because there was no way of, no way around it… [at the time] she actually broke it [her ankle], my dad was coming out of the hospital and she was just going in and they were like one floor apart…they told me at the time that they were trying to get her in a home and I thought thank God, because when she was home alone when he was in the hospital it was bad.

During the interviews, Dan and Bob expressed great sadness and loneliness about being separated from their wives. During the first interview, Dan described a brief phone conversation with his wife, the only contact they'd had in the five and a half weeks since his hospital admission, and explained how much they missed one another.

In describing his frustration with the different "stories" he'd been told about how long he would have to wait during the 15 months since his application for reunification with his wife at her LTCH was first accepted, Bob made the following observation:

"Especially in these years, you know, in your eighties, not that much time left, they could be a little more careful about splitting couples up."

Both Sarah and Alan expressed great frustration about the length of time it was taking to reunite their parents in the same LTCH. Alan described in stark terms the burden of waiting for reunification:

> It sounds melodramatic but he is going to die if they don't put them together. …And if he dies in here I'm going to be their worst enemy. ... I mean it's a matter of time, his days are numbered…I just want him and my mom to have some time…So that's what I have been feeling. [yeah]. It's exasperation, it's gone beyond frustration and it's oh well, the list, the statue, the policy.

Given the length of time that Alan had been advocating that his parents be reunited, he was very well informed about the rules and regulations regarding the placement process for LTCHs in Ontario. Overall, he highlighted a process of "leap-frogging" whereby the stated priority of reuniting couples in the same LTCH is continually over-ridden by the priority to seek crisis placement for individual patients in the community and in the hospital. He went on to say that these conflicting regulations (some of which he could name by their statute number) created a "catch-22" for patients.

> So unless all of a sudden there are no crisis people on that list they are going to keep jumping my dad and he'll never move in there. What are the odds?…This is a catch-22. And she [the assistant to MPP] said, our hands are tied, CCAC says our hands are tied and we have no control and the social worker says it's up to CCAC, the [nursing] home says it's up to CCAC and CCAC says no, it's up to the home [LTCH], it's the social worker, it's this.

Alan summarized his concerns by stating, "If someone tells me one more time that that is the way the system works; the system is broken; it needs to be fixed."

Unfortunately, the single interview with Frank did not provide much detail about the circumstances surrounding reunification with his wife, and no interview data was

available from his family caregiver who declined to participate in the study. However, the recruiter for this patient did describe some of the background that brought the patient to hospital and the circumstances around his eventual reunification with his wife at the LTCH they had both applied to. This reunification happened only 11 days after he was designated ALC. In reflecting on the reason that this reunification occurred so quickly, the recruiter mused about the relatively poor reputation and short wait list of the LTCH to which the patient and his wife had applied..

I Never Thought I'd End Up My Life Like This

The third major theme for this study is 'I never thought I'd end up my life like this.' This theme was identified across the narratives of patient participants only. Over the course of multiple interviews, four of five patient participants described struggles they were experiencing that related to their concept of self. This theme is composed of three sub-themes: (a) their view of the past as filled with freedom, movement, and meaningful activity, (b) their view of the present whereby they said 'I never thought I'd end up my life like this', and (c) their view of the future whereby they said 'At my age, what is there to hope for?' These sub-themes will be explored by describing how they were uniquely expressed by the patients in this study.

A) The Past: "I Was on the Go All the Time"

In speaking about their experiences before coming to hospital, patient participants provided a glimpse into their view of their past selves. Though each patient narrative was unique, a common thread that emerged across narratives was their view of themselves as

free to move and engage in meaningful activity, as captured by the phrase "I was on the go all the time".

In the first interview, each of the patient participants was asked to describe what their life was like before hospitalization. It was often interesting to note where each participant chose to begin this description. Dan began with an account of himself as "an athlete and a worker." He spoke of learning to box as a child of 14 years in order to defend himself as an under-aged worker, forced by his father to earn money to support the family. He concluded this story by saying,

> My father… had no use for us except to work and bring home the money and then he would steal anything we had. So we didn't have much saved till I got married. Then I said, "The bird's flown the coop, I'm gone, to have my freedom."

It seems that his choice to start his narrative here was significant to understanding his view of his past self. At least two things are apparent from this account: he saw himself as active and athletic in his younger years, and he valued greatly the freedom that was associated with his marriage and subsequent move away from the restrictive demands of his father. Despite the contrasting perspective that his daughter provided when she said that he hadn't been out of the house for three or four years prior to this hospitalization, Dan's account of his life before hospitalization spoke very little about these limitations and emphasized the freedom, within certain limits, that he experienced while living at home with his wife and daughter. In striking contrast to this, his description of the events leading to this hospitalization concluded with a dramatic and violent account of being forced from his home and confined in hospital. This suggests a definitive break with a preferred view of his past. Though most would call into question

his idealized view of his life just before hospitalization, it seems clear that he viewed it as significantly better than his present hospitalized state since life at home represented a time of freedom in contrast to his present experience of being held "hostage."

In her description of her life before hospitalization, Teresa conveyed a similar sentiment of freedom to do and move as she pleased.

> Well, when I lived alone I worked, I was retired, I did volunteer work from my church, I was on the go all the time. And I loved to walk, I walked all over the place, very seldom did I take a bus.

In contrast to this, Teresa commented on the dissatisfaction she felt about her current situation in hospital, saying "I think it's because of the inactivity, you've got nothing else to do." What she remembers and values about her view of her past self is freedom to be active and moving; 'on the go', as she says. This past activity was also very meaningful for her, involved as she was in mission work and worship with her church, a central and important community in her life. Her present circumstances are so difficult for her, then, because she is not free to move, and is not engaged in the kind of meaningful activity that she still values so highly.

Bob said in the first interview "I thought [I was in] great shape for a man my age. Yeah, I got around well, I walked every place." He spoke about how he liked to be with people, and how "every morning I used to go to Limeridge mall for coffee with a few fellows." When he reflected back on the larger sweep of his life, he said the following.

> We had eighty good years you know, and I've traveled the world, I've been a lot of places a lot of people never get. …. But I've done a lot, I've seen a lot, I've had a good life 'til they took my wife [to a LTCH]. She was a real smart lady in her day, anybody she ever went to work for she ended up running the company… really sharp woman.

What emerges, therefore, in Bob's account of himself and his past life is once again the value he placed on his ability to be active and to move freely, as someone in 'great shape' for a man his age. He valued relationships highly, including family and a faithful circle of longstanding friends, and described meaningful activities that involved 'going out' and 'traveling' together with these people. His present circumstance is devoid of these kinds of activity given his dependency for all movement. In anticipation of one of his friends coming to celebrate his birthday with him in hospital around the time of the second interview, he said that he was still holding out hope that he could once again walk so he could manage the steps at a cherished night spot he and his friends used to frequent.

When asked about her life before hospital during the first interview, Nancy began by talking about the death of her husband in 1982. Her view of that past, before his death, recalled a time of activity. However, "after my husband died there's nothing doing you know, because your husband is gone." Her view of the present, which she described as "boring, and I mean, I'm lying there all the time" thus seems to be fairly continuous with her view of the more recent past.

> I: What was your life then, after your husband died, like? What was it like?
> P: Well there was quite a few friends around that had lost their husbands and we'd go out, …once a week for lunch … and then you've got the rest of the whole day…because the girls are too busy you know, doing something.

Her view of a meaningful past for herself, then, seems still to date to a time when her husband was living. He was a business owner, and she described briefly in the first interview the fullness of this time in their lives. She valued relationships with her two daughters, and spoke warmly about the circle of female friends and neighbours that she would regularly visit. What was so difficult for her in recent years was having these

neighbours and friends grow older and move away, so that many of these same friends were currently living in institutions with supportive care. Despite all theses constraints on her ability to connect with friends in recent years, resulting in what her daughter saw as her mother's social isolation, Nancy insisted on remaining in her own home right up to this hospitalization. Her daughter attributed this fact to Nancy's stubborn unwillingness at the time to accept any help in the home or any suggestions about alternate places to live.

Frank began his account of his past by talking about the house he and his wife used to live in before his present apartment, and by describing his work life as a butcher. Although Frank spoke very little during our one interview together, it was interesting once again that rather than starting as requested with an account of his life "just before" hospitalization, he chose to return to a time of life when he was active and engaged in his work. However, unlike the other patient participants, he seemed much less discontent with his present circumstances in hospital. He appreciated that fact that he felt 'safe' at the hospital.

B) The Present: "I Never Thought I'd End Up My Life Like This"

Most of the patients described their view of their present situation and its possible futures as discontinuous with their past experience and previous notions they had about their future. Overall, they seemed to express an uncertain, almost bewildered, concept of self. The phrase 'I never thought…' was used by two of the patient participants in this context and captures well this sense of uncertainty or bewilderment they were struggling with. It would appear that their present, unexpected and difficult circumstance had

disrupted their past conception of who they were and what possibilities the future might hold. The present struggle they described about their concept of self seemed to be happening on two fronts. First, they were struggling to come to terms with their recent significant decline in their functional abilities and the restrictions on their freedom of movement and meaningful activity that this represented. Second, they were struggling to imagine themselves in a new place, given the decision that had been made to move from their previous home to a place where they will be dependent on others for care and support.

During the third interview on the morning of transfer to a LTCH, Dan commented that "I never thought I'd end up my life like this." He seemed much more pensive and uncertain in this interview, in contrast to the previous interviews where he expressed himself in strong and direct terms that included many expressions of emotion like anger and sadness. At this interview, he seemed resigned to his circumstance.

Interestingly, Teresa appeared to be experiencing similar bewilderment about who she was in her present situation when she made the following comment during her second interview "I never thought in my life I would be one to complain." This interview was filled with a litany of complaints she had about her present situation, in marked contrast to the first interview where she said very little that was critical in nature. During this interview, she struggled with feeling badly about this new, unexpected part of herself. As well, in contrast to her remembered past full of meaningful activity, Teresa in the second interview lamented that she was 'not going anywhere':

> The days are long, the nights are longer and of course in every room they have a great big clock that tells you exactly to the minute. So your life is passing you by and you're not going anywhere.

For someone whose life had been "on the go" and filled with meaningful activity at her church in worship and volunteering, she was struggling with who she was and what future was possible given this circumstance.

Bob expressed great remorse about the disruption of his past life and sense of self: "Then it all tumbled down. Everything I worked for all my life is… [yeah] You gotta get rid of your house, that's going to hurt." In contrast to his remembered, active past full of meaningful activities and relationships, he emphasized in dramatic terms that previous things he had valued so highly had 'tumbled down.' He found it particularly hard to imagine selling his house, the place where he had lived for almost 50 years with his wife and where his son had spent most of his growing up years. His use of the phrase 'Everything I worked for all my life' suggests again a definitive break with what he had valued so highly in the past and emphasizes the tremendous loss he is currently experiencing.

In a similar vein, Nancy talked in the first interview about being cut off from her past in the sense of no longer being "known" by her neighbours while she was living at home.

> I've had about five different neighbors on each side you know, because we were the same, we moved there and had the girls and that. Everybody else has moved out and gone someplace else, so they don't even know me now … like nobody's got time for you [yeah] they really don't.

Nancy spoke in the same terms about not being 'known' by staff members at the hospital. This concern seemed to emphasize the value she had placed on important relationships in

her life and the lack of those in her present circumstance: “They don’t even know who I am you know… And those girls come in and they’re doing their job and they don’t have time to talk to you.” Overall, this seems to raise a question in her mind about who she is in light of the fact that she is not known by others in this way.

Unlike the other patient participants, and while acknowledging his present inactivity, Frank was not distressed by his present circumstances, and seemed to feel confident about a continuity of his sense of self: “Never really worried about anything my whole life ...I just take things as they come [right] and roll with the punches. Not a lot you can do.”

C) The Future: “At My Age, What Is There to Hope For?”

Patient participants had a mostly negative view of their future. When asked what they hoped for, the responses ranged from tentative hopefulness (Dan and Frank) to trusting pessimism in the face of uncertainty (Teresa) to a conviction that there was no future (Bob) to resignation expressed with the words ‘At my age, what is there to hope for?’(Nancy). It is the phrase provided by Nancy that has been used to capture the overall sense of the patient participants’ collective view of their future. For all of the participants, this future was uncertain and difficult for them to imagine in any detail. This future was also discontinuous with the past experiences they had previously described. As a result, aware of their age and the recent decline in their health, most participants were pragmatic and frank in speaking about their own mortality and the possibility that the end of their life might be near. However, in most cases this pragmatic view of the

future did not preclude their identification of very modest hopes for a future which was better than their present circumstance.

When asked what he hoped for in the last interview, Dan said "A better life." He also said "I hope … they're [the LTCH] more up-to-date." and therefore better able to help him walk again in contrast to the hospital that he felt had devoted such poor effort in this regard.

Throughout all of the interviews and the many challenges she described therein, Teresa consistently depicted her Roman Catholic faith as a sustaining and nurturing presence in her life, and this sense extended clearly into her view of the future. Teresa generally had a tendency toward a pessimistic view of her future as evidenced by repeated comments similar to this one made in the first interview: "I can't see in the future any improvement [in my illness and function]." She was also quite willing to accept her own mortality, saying she found it hard to "see the obituaries everyday, young people dying of heart attacks and you think no, Lord, why don't you take me and let them live?" Despite these tendencies, she held strongly to the belief that one had to trust God despite uncertainty about ones' future, "living day-to-day… in God's time."

In the third interview, Teresa spoke further about the uncertainty she was feeling regarding her future and the many challenges she was facing and said "I think you get accustomed to things and you adjust or you go crazy, one or the other." Despite these challenges, and her awareness that things might never improve, her orientation toward learning to 'adjust' to the changes in her life suggested a willingness to continue to

struggle to create a meaningful future. It seemed that this willingness to struggle was rooted in her continuing trust in God.

From our very first meeting, Bob was very clear about his view of his future at the LTCH, saying "I don't have a future." Like Teresa, Bob had a pragmatically realistic view of his future. In thinking about his hospitalization, he said "I've been laying for two months. That's no good." Given his past experience with chronic illness and repeated cycles of exacerbation and recovery, Bob recognizes that his inability to rebound from this acute illness is a sign that he might not recover this time. The only faint hope he maintains is that the LTCH might be able to accomplish with his function what the hospital was unable to do.

Like other patients, several times throughout the interviews Bob spoke about his own mortality and the fact that he did not expect to live much longer. In the end, he expressed only one heartfelt hope which was to "spend the rest of my life with my wife in close proximity." This was clearly understood by him not to be a long time.

Nancy had a resigned view of her future. In the first interview, she said, "At my age, what is there to hope for?" At the second interview, when speaking about her impending move to the Retirement Home, she said "Like, I'm just putting in time, doesn't bother me going anywhere else, but it's going to be the same old thing you know. It's not your house."

Nancy was also quite willing to speak about her own mortality and said that she was not afraid to speak about her death. However, it does not seem that her sense of resignation had to do with concern that her illness and function would not improve but

more with feeling she could not see a meaningful future for herself given that she would be living in an institution. As she said, 'It's not your house' and at that juncture, she was not hopeful that she would find any experience that would be fulfilling in this new setting. She felt it would never feel like home to her.

When asked what he hoped for, Frank responded "I hope to get my health back." He went on to muse that he hoped that he and his wife could eventually return to living together at home with supports after a time recovering in LTCH together.

CHAPTER 6: DISCUSSION

Discussion of Findings

The current study makes an important contribution to our understanding of the patient and family caregiver experience of ALC. The major finding of the current study was that *uncertainty* was a significant part of the experience of ALC for these participants. Uncertainty was apparent in each of the three main themes which were: *I don't know*, W*aiting*, and *I never thought I'd end up my life like this.* This discussion chapter will explore the major theme of uncertainty as it was manifested through the findings of the current study, and connect these findings with related literature. The implications of this study for practice, policy, education and research are discussed, followed by a presentation of the study limitations. In the discussion which follows, I indicate that I am speaking about my study by consistently using the phrase 'the current study.'

I begin the discussion with an examination of the overall finding of uncertainty in the current study. I then examine specific manifestations of uncertainty related to the experience of ALC that were apparent in all three dimensions of Clandinin and Connelly's framework for the narrative study of experience (Clandinin & Connelly, 2000). First, in the personal dimension, I will discuss participant descriptions of uncertainty about their self-concept. Second, in the dimension of interactions with the hospital environment, I will discuss participant experiences related to uncertainty that occurred in four different areas: (a) not knowing - lack of information about important processes related to the hospital, placement, and medical assessment, diagnosis, and

prognosis; (b) not knowing - inadequate participation in planning for discharge; (c) lack of mobility; and (d) lack of meaningful activity. Finally, in the dimensions of time and place, I will discuss uncertainty as it related to waiting for placement.

Uncertainty and the Experience of ALC

The major finding of the current study was that *uncertainty* was a significant part of the experience of ALC for patients and family caregivers. This finding of uncertainty has not been previously noted in the ALC literature. Other studies of patient experience have emphasized themes that resonate with the findings of this study such as lack of information (Doleweerd & Berezny, 2009; Swinkels & Mitchell, 2009), and feeling anxious about the future (Kydd, 2008). None, however, have reported the combination of findings that have resulted in my view that uncertainty is a central part of the ALC experience ALC.

Uncertain Self-Concept

One of the major themes for this study, *I never thought I'd end up my life like this,* related directly to the personal dimension (internal conditions including hopes, feelings, aesthetic reactions, and moral dispositions) described by Clandinin and Connelly (2000). This theme addressed stories that participants told about their past, their present, and their future. When they spoke about their past life, before hospitalization, patients told stories that conveyed freedom, movement, and meaningful activity. When they spoke about their present experience in hospital, however, participants described it as discontinuous with this remembered past and what they had previously imagined their future self would be. Overall, they seemed to be struggling with an uncertain, almost

bewildered, self-concept. This was captured in the phrase “I never thought” which was used by three different patients.

The findings in the current study about uncertainty related to self-concept makes a new contribution to the research literature on ALC. Previous studies of the experience of ALC have not commented about uncertain patient self-concept. Two studies do speak about patient emotions related to the experience, specifically anxiety about the future (Kydd, 2008) and low mood (Swinkels & Mitchell, 2009).

Patients in this current study who expressed an uncertain self-concept were in the midst of recovering from an acute illness episode that almost certainly resulted from an exacerbation of an existing chronic illness. Some of the larger research literature on self-concept related to chronic illness, specifically concerning Alzheimer’s disease, does explicitly discuss the idea of uncertainty (Parsons-Suhl, Johnson, McCann, & Solberg, 2008; Pearce, Clare, & Pistrang, 2002). For example, Pearce, Clare, and Psitrang (2002) found that uncertainty related to changes in their memory ability made it more difficult for participants to maintain a previous sense of self, while Parsons-Suhl, Johnson, McCann, and Solberg (2008) found that participants felt uncertain about what their bodies could and could not do. The current study supports this view of uncertain self-concept in chronic illness.

Although not explicitly mentioned as an issue of uncertainty, other literature about the experience of chronic illness does discuss changing self-concept. For example, Charmaz (1995) points out that chronic illness disrupts the unity between a person’s concept of the relation between their body and their sense of self. She describes a variety

of modes in which people live with chronic illness including ignoring, minimizing, struggling, reconciling self to it, embracing and adapting. In the current study, an examination of the stories participants told about their lives before and during hospitalization suggests that a variety of these modes of living with chronic illness were represented, with struggling being a particularly prominent mode in their present experience in hospital. Charmaz (1995) also describes a process whereby some people with chronic illness go through stages of adapting to impairment. Due to the post acute illness timing of the current study, it is difficult to characterize the nature of the experience of each of the patient participants in light of this stage analysis, however, it is clear that they are all in a common period of living soon after a recent significant deterioration in their functional ability and are therefore just beginning a much longer process of learning to live with reduced, if not yet fully certain, levels of ability. Unlike the analysis of Charmaz, however, the experiences described in this current study include a component of relocation as an added layer of challenge to participants in learning to live with chronic illness.

Patient participants in the current study struggled to think about their self in the future relative to how they had previously imagined their future self. This was exemplified in their comments related to the phrase “I never thought.” This difficulty was quite understandable given the great uncertainty that they described about their current life situation. This uncertainty included questions they had about whether death was imminent, about the level of mobility and functional ability they could hope to recover,

about the plans for a supported place of care where they would be living and about the possible circumstances and timing of being reunited with their spouses.

The research literature on self-concept includes the idea of possible selves. Markus and Nurius (1986) use the term *possible selves* to describe the way in which people think about themselves in the future. It has to do with a person's ideas about what they might become, what they would like to become, and what they are afraid of becoming, and it includes their thoughts about hopes, fears, goals and threats. They observe that possible selves are important because they provide incentives for future behaviour as a person sets goals to move toward a desired possible self or to avoid an undesired possible self. They point out that the concept of possible selves allows a person to make a more direct connection between motives and actions by specifically imagining themselves in a goal situation to which they aspire. In the current study, participants describe great uncertainty about their possible selves. Unfortunately, the literature on possible selves suggests that the absence of clearly imagined possible selves might hinder a person's motivation to formulate and implement goals toward recovery from an acute illness episode.

In summary, the finding in the current study about uncertain self-concept makes a new contribution to the literature on experiences of ALC. Although literature related to chronic illness does address the issue of changing self-concept, and in the case of Alzheimer's Disease, specifically examines the experience of uncertainty in the midst of chronic illness, the current study adds a new perspective on this literature by including relocation as an added layer of challenge for these particular patients living with chronic

illness. Finally, the finding of uncertain possible selves as a component of the struggles with self-concept that patients in the current study experienced has implications for helping motivate patients toward future goals.

Uncertainty and Interactions in the Hospital Environment

Four of the themes in the current study reflected participant experiences of uncertainty related to interactions in the hospital environment. These themes will be discussed under the following headings: (a) Not Knowing: Lack of Information; (b) Not Knowing: Inadequate Participation: (c) Lack of Mobility; and (d) Lack of Meaningful Activity. Unlike the uncertainty described about patients' self-identity which existed within the person, however, uncertainty in this context existed in the interaction between the participant and the social and physical environment of the hospital. This is significant because findings in this area will imply strategies that might alter this environment to better manage the experience of uncertainty described by participants.

Not knowing: Lack of information. The findings about lack of information are congruent with previous studies of experiences of ALC (Doleweerd & Berezny, 2009; Swinkels & Mitchell, 2009). Doleweerd and Berezny (2009), for example, identified inaccurate and unavailable information as a main deficiency noted by family caregivers.

Patient and family caregiver concerns about lack of information reflect problems documented in the larger research literature on hospitalization (Flacker, Park, & Sims, 2007; Grimsbo, Finset, & Ruland, 2011; Higgins, Joyce, Parker, Fitzgerald, & McMillan, 2007; Huber & McClelland, 2003; Makaryus & Friedman, 2005). For example, Markaryus and Friedman (2005) reported that less than half (41.9%) of patients surveyed

at the time of discharge were able to name their diagnosis, and fewer still had a complete understanding about their medications, reflecting the experience of some of the participants in the current study who didn't know information about their diagnosis. Grimsbo, Finset, and Ruland (2011) in their study of email communication between adult cancer patients and oncology nurses identified unmet information needs following contact with the health care system captured under the theme *I have a feeling of hanging in the air*. This theme echoes the uncertainty captured in the theme of *I don't know* identified in the current study.

The larger research literature on hospitalization also documents the information needs of family caregivers. Higgins, Joyce, Parker, Fitzgerald, and McMillan (2007) examined the experiences of 10 family caregivers of older adults in Australia through single interviews conducted while the patient was still in hospital. The study highlighted the importance that family caregivers attached to receiving accurate information concerning the current and future care of the older patient, a theme strongly endorsed by family caregiver participants in this current study. A study by Huber and McClelland (2003) noted a lack of congruence between patient and caregiver preferences for information in the process of planning for discharge from hospital. Findings in the current study demonstrated a number of differences between the perspectives of patients and family caregivers regarding the same hospitalization experience, and this may extend to the area of information needs though this was not specifically explored.

Finally, the research literature reports that nurses are aware of the communication challenges that adult patients and family caregivers face in getting the information they

need such as poor coordination and poor handover of information in preparation for discharge, attributing these problems to barriers such as lack of time (Atwal, 2002; Kalisch, 2006). Participants in the current study also voiced strong concerns about problems with communication, and at the same time, acknowledged some of the same barriers to communication such as lack of time. However, more complete analysis of the problem of missed opportunities for nursing care (Kalisch) revealed a number of other barriers that contributed to the problem of poor communication in the realm of hospital nursing care as captured under the themes *it's not my job syndrome, ineffective delegation, habit,* and *denial*.

Not knowing: Inadequate participation. Almost all participants in the current study expressed frustration about their lack of awareness of the plan for their discharge. In many cases, the barriers to full participation can be thought of as indirect or passive. Teresa initially trusted that the hospital would take care of the arrangements for her discharge. At the time of transfer, however, she felt very upset about how poorly informed she was concerning these plans. Similarly, at no time did Nancy speak strongly about not being included in the discharge planning process. However, when it came time for discharge, she expressed much distress about various aspects of the plan for discharge that she did not understand. My impression is that both patients were informed on an infrequent basis of the more general plan for their discharge but were not actively engaged in preparing in an ongoing way for the specific manifestations of this plan as the time for discharge approached. The passive approach implied by this characterization of the planning process appears not to have served either patient well in this circumstance

given their obvious dissatisfaction with the final result and the uncertainty they felt about the plans at the time of discharge.

These findings are consistent with the idea already presented in the ALC literature that disempowerment related to poor communication is a barrier to full participation (Swinkels & Mitchell, 2009) and that patients had “little choice” about the plans being prepared for their discharge (Kydd, 2008). The larger literature on hospital discharge planning includes a Swedish study on older female patient participation in a discharge planning conference (Efraimsson, Sandman, & Rasmussen, 2006). This study found that patient fatigue, coupled with being significantly unprepared for the content and process of the meeting, undermined the patient’s ability to participate in any meaningful or substantial way in important decisions regarding their discharge plan.

The current study also provides examples of more active exclusion from the planning process. The most striking example was that of the patient Bob who was extremely upset that he was excluded from a crucial discharge planning meeting. As well, the family caregiver Barb was disturbed that, contrary to her prior expectations, no discharge planning meeting ever occurred throughout her mother’s hospital stay. These findings about patient and family caregiver participation suggest that a term like ‘disenfranchisement’ might characterize the experience of ALC patients in relation to their participation in the discharge planning process better than the term ‘relinquishment’ as previously proposed (Swinkels & Mitchell, 2009). *Disenfranchisement* (2011), understood as a state of being deprived of civil or electoral privileges, better captures the idea that circumstances outside the control of the individual have prevented a person

from participating whereas *relinquishment* (2011) suggests that a person chose to abandon or surrender the possibility of fuller participation. Using Roberts (2002) commentary about degrees of citizen power, one might locate these participant experiences as a form of tokenism rather than true active engagement in the planning for their care.

Lack of mobility. Participants in the current study were very concerned about the lack of assistance to mobilize or the lack of careful assessment of the reasons behind their inability to walk and worried about the long term implications of this. A number of participants spoke about the intermittent and unreliable schedule of the limited physiotherapy they did receive and made special note of the lack of assistance on weekends when they felt they lost the little improvement they might have gained during the week.

Swinkels and Mitchell (2009) reported *immobility* as a theme in their study of delayed discharge and found that older patients were well aware of the known detrimental effects of poor mobility on their health. In the larger body of research literature related to hospitalized older adults, Callen, Mahoney, Grieves, Wells, and Enloe (2004) found that few of the older patients on the medical units of an academic hospital who were evaluated as able to walk actually walked during the periods of observation from 8 AM to 8 PM.

The detrimental effects of lack of mobility among older hospitalized patients is a well-documented problem in the research literature (Brown, Friedkin, Inouye, Friedkin, & Inouye, 2004; Fisher et al., 2011; Zisberg et al., 2011). For example, Brown, Friedkin,

and Inouye (2004) found that low mobility and bedrest were common in hospitalized older patients and were important predictors of adverse outcomes resulting in functional decline, and considered it an iatrogenic phenomenon, that is, an outcome caused by the hospitalization itself that could have been prevented. More recently, Zisberg and colleagues (2011) reported similar findings.

The findings of poor mobility and lack of assistance to mobilize in the current study, then, build on the available research literature related to hospitalized older adults. Participants in this study, congruent with the literature, were concerned about the detrimental effects of lack of mobility on the overall outcome of their hospital stay, suggesting that strategies to improve mobility are an important implication of the current findings.

Lack of meaningful activity. Participants in the current study spoke eloquently about the significant lack of meaningful or purpose directed activity during their time in hospital while designated as requiring ALC. Although patients reported organized times of socializing and recreation, they expressed a number of concerns about the activities including their limited duration and frequency, the uninteresting nature of the activities, difficult social interactions with the other patients in the group that left some feeling uncomfortable or poorly matched socially, and the problem of worsened inactivity on the weekends. Overall, most patient participants described spending the majority of their day in their own bedroom, lying in bed. The effects of this inactivity were described in such comments as watching the clock, the length of a 24 hour day, feeling bored, and complaining because of the inactivity.

Consistent with the current study, lack of meaningful activity during delayed discharge was also described by Swinkels and Mitchell (2009) who reported that this lack of activity was associated with expressions of low mood and frustration by participants. Kydd (2008) found that participants reported being bored during their experience of delayed discharge.

The larger body of research literature related to hospitalized older adults also reports concerns regarding lack of meaningful activity (McKee, Harrison, & Lee, 1999; Nolan, Grant, & Nolan, 1995). For example, Nolan, Grant, and Nolan (1995), in their study aptly titled "Busy Doing Nothing", found that older patients spent most of their time being inactive and that almost all of the meaningful or constructive activity that they did engage in was informal in nature and initiated by the patients themselves. In their report, they provide an extended account of one patient, 'Mr. Peters', who was blind, confined to a wheelchair, and seen to be a less socially able patient. Mr. Peters spent the majority of his day sitting in the day room doing nothing (being *passive*, to use the study coding category). Although described as being initially stoical and uncomplaining, he eventually expressed dissatisfaction with his respite stay at the hospital. It emerged during the interview that his favorite usual activity at home was listening to talking books but neither he nor the staff at the day hospital had explored the possibility of providing this activity for him.

The above account by Nolan et al. (1995) is resonant with the story told by Teresa in the current study about her efforts to attend Mass at the hospital. Because of her initiative and persistence, Teresa was successful in finding a very meaningful activity for

herself during the last couple weeks of her hospitalization. In his case, Mr. Peters did not initiate the activity of talking books because he simply assumed it was not possible because the noise would disturb others. However, the authors wonder why the staff, who were not aware of this interest of his, "had not been creative in seeking ways in which Mr. Peters could have more constructively passed his time" (Nolan et al., p. 535). A similar question could be asked about the role for staff in Teresa's situation in getting to know her better, better understanding what might be meaningful for her, and assisting her to find meaningful activity like attending Mass. This question reflects a larger concern about missed opportunities for nursing care (Kalisch, 2006) which is explored in the implications for practice section to follow.

Uncertainty of Time and Place: Waiting for Placement

The theme of *waiting for placement* illustrated the way that uncertainty in the dimension of time contributed to participant's global experience of uncertainty while designated as requiring ALC. For participants in the current study, the duration of waiting for placement proved to be almost completely unpredictable. The length of ALC stay for the five patients in this study ranged from 11 days to 85 days. None of the participants indicated that they were given during the hospital stay useful estimates of the time that they would have to wait until placement. Three of the cases included the additional factor of waiting for couple reunification, and each of these cases varied greatly in the final wait time despite this common denominator. In the end, these three wait times ranged from 67 days for Dan to 42 days for Bob and, most unexpectedly, only 11 days for Frank. Even social work recruiters closely involved with the patients in the

study were at a loss to predict the likely timing of discharge for each of the five cases. In all five cases, discharge occurred suddenly with very little advance notice, less than 24 hours in two cases.

In their recent study of experiences of ALC in Ontario, Doleweerd and Berezny (2009) also reported on participant concerns about uncertainty concerning how long they had to wait for discharge to a LTCH. They reported that the uncertainty appeared to follow from the many complex factors that govern the placement of patients from hospital to LTCH in Ontario, including the lack of accurate information about wait times.

In summary, this *Discussion of Findings* has explored the major theme of uncertainty as it was manifest through the findings of the current study, and has positioned these findings within a larger body of related literature using Clandinin and Connelly's (2000) framework of inquiry into human experience. The current study provides an important new insight about the overall experience of ALC as a time of great uncertainty for patients and family caregivers. The current findings support existing literature concerning uncertainty about ALC wait times for placement, lack of information, lack of mobility, and lack of meaningful activity. Although this study's finding of inadequate participation in the discharge planning process is reflected in the literature, it expands on the notion of relinquishment put forward by Swinkels and Mitchell (2009) by suggesting the experience is better described by the idea of disenfranchisement.

Implications for Practice, Policy, Education and Research

These study findings have a number of implications for practice, policy, education and research. The major finding of the current study was that uncertainty is a significant and challenging part of the experience of ALC for patients and family caregivers. Thus, the central focus of the implications is on strategies to better manage uncertainty in the context of ALC. These implications will be structured using the Glasby framework to guide responses to problems associated with ALC at the individual, organizational, and structural level.

Implications for Practice

The findings from the current study have important implications for practice at the organizational and individual level. At the organizational level, practices should be developed to include: (1) more comprehensive strategies for teaching and information sharing; (2) more reliable scheduling of goal directed plans for physical therapy; and (3) better strategies to mitigate the negative effects of patient mix. At the individual level, the practice of staff members should include: (4) getting to know patients and families; and (5) better patient and family support in the midst of uncertainty.

First, at the organizational level, providing timely and accurate information to older patients and families is key to managing uncertainty in the midst of the ALC experience. There is a substantial body of literature related to managing uncertainty in chronic illness (Bailey, Wallace, & Mishel, 2007; Mishel, Germino, Gil, Belyea, & Laney, 2005; Penrod, 2007) which includes research based on Mishel's Uncertainty in Illness Theory (Mishel, 1988; Mishel, 1990; Mishel & Clayton, 2003). One of the key

insights of Mishel's Uncertainty in Illness Theory applied to chronic illness is that a patient's experience of uncertainty can be influenced through the provision of education and social support by a credible authority (Mishel & Clayton). Mishel and Clayton state that "as experts, health care providers… reduce uncertainty by providing information and promoting confidence in their clinical judgment and performance" (p.36). The discussion which follows suggests strategies for more effective communication of information based on the discharge planning literature.

The family caregiver Barb astutely offered the idea of an information package to be provided to patients and families about information related to the discharge planning process. Her central request was for a printed overview that would help her better know 'the right questions to ask.' The literature on discharge planning does acknowledge the importance of printed information. For example, Driscoll (2000) found that patients and family caregivers who received appropriate verbal and/or printed information had a lower incidence of medical problems following discharge.

Particular information needs identified by participants in this study about hospital processes were: names of wards and description of the general purpose or function of the ward; reasons for moves in hospital; day passes; availability of wheelchairs to assist transportation for day passes; better access to results of medical tests; and information about diagnosis and prognosis. Particular information needs identified about the discharge process were: overview of stages in the process; description of placement options including comparison of characteristics of LTCH and Retirement Home; criteria used to assess appropriate level of placement in LTCH vs. Retirement Home; role of the

CCAC in the discharge planning process and when and how to contact CCAC; suggestions for questions to ask in touring LTCH and Retirement Home; wait time estimates for LTCH and Retirement Home; clarification of financial issues related to placement and specifically information related to ALC co-payments; and description of the Assess and Restore program and its function in the larger placement process.

Although providing information in a printed form may address some of the concerns about lack of information as described in the current study, this is not a sufficient solution to the problem of addressing information needs in the discharge planning process. For example, Flacker, Park, and Sims (2007) in their survey of older patients following discharge found that many patients lacked important information despite hospital protocol that included a discharge information sheet. The literature on best practice related to discharge planning for older adults and family caregivers suggests that effective strategies must include active information sharing throughout the hospital admission, and early involvement of the family caregiver in all information sharing activities (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). Strategies to develop a more comprehensive approach to discharge planning within hospitals are essential to address the information needs of patients and family caregivers (Bauman et al., 2007). These ideas will be discussed further in the section on policy implications. Participants in the current study also commented on the potential value of the ward nursing station as an information centre and examination of the nursing station environment on different wards might identify opportunities to improve information sharing between patients, families, and members of the multi-disciplinary team.

Second, at the organizational level, the findings about lack of mobility suggest that strategies should be developed to promote and optimize goal directed plans of ongoing physiotherapy in order to address deconditioning and ultimately lead to greater patient independence and satisfaction. Improving the reliability of scheduling of these services could help to alleviate one source of uncertainty identified by participants.

Third, a significant challenge identified in the current study was programming across a wide range of patient needs, function and personality given the diverse nature of the patient mix on the ALC Ward. Although the issue of patient mix is a challenging one given the need to balance overall bed availability in the hospital with patient need, staff and administrators of the ALC Ward should be made aware that the wrong mix can have detrimental effects on the level of meaningful activity for some patients. It may be helpful, for instance, to provide more than one ALC Ward in order to allow more options to better accommodate varying levels of physical and cognitive function among patients, and to better accommodate those patients with behavioural challenges like wandering, or aggressive behaviour.

Fourth, at the individual level, staff members should understand the value of getting to know older patients and families in structuring meaningful activities with them. For instance, although nurses have an important role to play in assisting to mobilize patients, the literature suggests that in a hospital environment this does not always occur (Callen et al., 2004). Strategies to increase the frequency of nurse assistance with mobilizing patients may require unit specific examination of the root causes of the problem (Kalisch, 2006). However, a number of patients in the current

study reported that opportunities to simply move about their ward in a wheelchair would have been quite meaningful. Better assessment of patient needs and preferences, and better targeting of available resources to address those preferences and needs, may help to identify those patients like Teresa who would benefit from less intensive types of mobility activities. As well, the current study demonstrated the importance of carefully considering the appropriateness of recreational activities as a number of participants did not find the structured activities to be meaningful. Getting to know individual patients and their particular interests, and offering a variety of activities that might appeal across a range of interests, are both important ways of developing meaningful program activities for older patients.

Finally, at the level of individual practice, the finding about uncertain self-concept suggests the possibility of providing support to patients in the midst of this experience. Uncertainty in general causes discomforting feelings that range from fear to frustration to an acceptable level of doubt (Penrod, 2007). In considering strategies to directly address a patient's experience of uncertainty, Penrod cautions that the primary emphasis on information provision proposed by Mishel's Uncertainty in Illness Theory may not always best represent what is needed. She argues that when the mode of uncertainty is existential in nature and related to learning to live with prolonged uncertainty (thereby echoing the work of Charmaz (1995) about adapting to chronic illness), the strategies of intervention should also be focused on helping patients with personal introspection and seeking a sense of personal growth (Penrod). Supportive listening, then, has an important role to play in easing the patient experience of

uncertainty. Frank (1998) has commented that just listening is a part of the health professional's role and that the simple act of a patient telling their story can lead to changes in that person's life. All staff can have a role in providing this support.

Implications for Policy

The findings from the current study have important implications for policy at the structural and organizational level. At the structural (regional and provincial) level, health system policies should be developed for older patients designated as requiring ALC that: (1) reduce the occurrence of ALC; (2) better support allocation of resources for mobility and meaningful activity; and (3) better support strategies to improve patient and family experiences related to LTCH wait list management, couple reunification, and the ALC co-payment. At the organizational level, policies should be developed that: (4) encourage patient and family caregiver participation through a comprehensive program of discharge planning; and (5) name and describe the organizational environment in a more patient and family centred way.

First, at the regional and provincial level, policies should be developed that result in more comprehensive strategies to reduce the occurrence of ALC among older patients. In general, hospitalization is hazardous for the health of the older patient, and every effort must be made to reduce the time in hospital when that stay is no longer necessary (Callahan, Thomas, Goldhirsch & Leipzig, 2002). The findings in the current study about patient and family distress related to the uncertainty of the ALC experience are congruent with this view. As described in the literature review in chapter 2, evidence regarding solutions is limited at this time, but more comprehensive strategies simultaneously

addressing all three levels in the Glasby (2004) framework hold some potential. For example, an RCT in Canada evaluating the effectiveness of a comprehensive system of integrated care for older adults demonstrated a 50% reduction in ALC while maintaining patient satisfaction and improving family caregiver satisfaction (Beland, 2006).

Another specific approach to reducing ALC advocated in the UK and Canada has been increasing options for what is known as intermediate care (Glasby et al., 2008; Ontario, Expert Panel on Alternate Level of Care, 2006). *Intermediate care* refers to short term care that is intended to provide a community-based alternative to hospital in order to avoid admission completely or allow earlier discharge from hospital (Wilson, Richards, & Camosso-Stefinovic, 2007). Although increasing intermediate care holds potential to reduce ALC, evaluation of such options must take into account patient satisfaction. Concerns about tensions in the relationship between the hospital and community care sector may pose a barrier to realization of the potential of these options if such measures are not coupled with structural level system changes to support them (Glasby et al., Wilson et al.).

Second, at the regional or provincial level, policies should better support allocation of resources for mobility and meaningful activity for older adults who are designated as requiring ALC. The overall effect of lack of mobility is that some patients, because of deconditioning secondary to low mobility during their ALC hospitalization as discussed earlier, will end up requiring a more intensive and more expensive level of care than otherwise would have been required. This has implications for the way in which hospitals are paid for non-acute beds. Once a patient is designated as requiring ALC, the

hospital receives a lower level of payment and adjustments are made to maintain expenses consistent with this lesser level of funding including the reduction in such services as physiotherapy and recreation therapy. In a similar way, the combined findings about lack of meaningful activity, uncertain self-concept, and uncertain possible selves (see discussion of findings) suggest the possibility of poor functional progress in the case of some older patients and a higher probability of more expensive level of care at discharge. Therefore, policy changes should better support hospitals in addressing the need for greater patient mobility and more meaningful activity.

Third, at the regional and provincial level, policies should provide strategies to address problems related to LTCH wait list management, couple reunification, and the ALC co-payment. Doleweerd and Berezny (2009) have previously noted this same concern about wait list management in Ontario. This finding also has implications for further research to determine the accuracy and effectiveness of the current system of determining and communicating wait times to hospitals and the factors influencing this reporting.

Three of the cases in the current study involved situations where patients were subject to uncertain times of waiting to be reunited with their spouses in a LTCH while designated as requiring ALC. This led to great feelings of distress and sadness among all three of these patients and their families. Although media reports at the time suggested that provincial legislation was being reviewed in order to address this concern (Wilson, 2010), the administrative catch-22 described by participants in the current study between the urgency of couple reunification versus urgency regarding crisis placement in LTCH

suggests that analysis and solutions to this provincial policy dilemma may require concerted effort to resolve.

Finally, policy at the provincial level concerning the ALC co-payment should be reviewed in light of the concerns expressed in this study. Participants expressed frustration about: (a) the financial dilemma for married patients of simultaneously supporting their house expenses, placement expenses for a spouse in LTCH, along with the ALC co-payment; (b) the poor level of service received relative to what would be available in the more appropriate place of care; and (c) the requirement by the hospital to pay additional fees for services like parking that would normally be part of basic services at the more appropriate place of care. It would be helpful, for instance, to create specific exemptions for patients in difficult financial dilemmas like those faced by married patients simultaneously maintaining three different places of care.

Fourth, at the organizational level, policies should encourage patient and family caregiver participation through a comprehensive program of discharge planning. As discussed earlier, Baumann et al. (2007) described several factors that prevented delays in discharge including discharge teams, systems to monitor and communicate patients' progress, robust patient choice protocols, and responsive transportation, an interagency discharge protocol (e.g. between hospital and CCAC), simple and efficient early notification system of estimated discharge date, and interagency monitoring of individual discharges and weekly assessment of delays.

Comprehensive approaches to discharge planning must include strategies to enhance the participation of patients and families. Like the UK (Roberts, 2002), the

province of Ontario, has recently enacted Bill 46 which has the goal of increasing patient participation in healthcare (Ontario, Hon. D. Matthews, 2010). As discussed in the practice section, discharge planning should include better, earlier, and more frequent communication and education with the patient and family. As well, in seeking to realize more patient centred care, the ideal at the heart of Bill 46, it is essential to 'get to know' individual patients in order to better understand their particular needs and preferences, and to seek ways to proactively engage them in the discharge planning process. Toward that end, a specific person on the multidisciplinary team designated as a discharge advocate might improve participation in the discharge planning process (Jack et al., 2009; Naylor, Brooten, Campbell, Jacobsen, & Mezey, 1999). For example, Jack and colleagues found that adult patients reported higher levels of preparation for discharge when the discharge process included a nurse discharge advocate, a written and patient specific after-hospital care plan, and a telephone call by a pharmacist two to four days after discharge.

In the current study, social workers filled part of the functions described for a discharge advocate. However, participants noted that the social worker changed when the patient was moved to a different ward in the hospital. Efforts to further define the elements of the discharge advocate role and to ensure better continuity of this role may increase participation and further reduce uncertainty for patients and family caregivers.

Finally, at the organizational level, policy should be developed to name and describe the organizational environment in a more patient and family centred way. The findings demonstrated that many of the wards were named in a way that might make

sense from the perspective of service providers but did not convey meaningful information to patients and families about their own care.

Implications for Education

The findings from the current study have important implications for education at the individual, organizational, and structural level. At the individual level, education should be targeted to all direct care hospital staff involved in the care of patients designated as requiring ALC. The overall goal of this education should be to raise awareness about the elements of comprehensive discharge planning for older adults including those who have been designated as requiring ALC. This education could incorporate specific material concerning ALC including its significance within the larger system of care for older adults, a general description of the placement application process with a particular emphasis on distinguishing LTCHs and Retirement Homes, and a summary of findings from the current and other studies about experiences related to ALC. This education should also emphasize the importance of effective multidisciplinary team communication and the importance of patient and family caregiver participation in the discharge planning process.

Education at the level of the individual healthcare provider should also be targeted around the findings related to lack of mobility and lack of meaningful activity. First, staff on the ALC Ward of the study hospital should receive education on the care of older adults which includes emphasis on the importance of maintaining mobility and participation in meaningful activity of older adults to prevent deconditioning and improve their overall quality of life. As well, emphasis should be placed on the overall

finding of uncertainty in the experience of ALC and the role for supportive listening in assisting patients and families with this important life transition. Nursing staff on all wards of the hospital providing care to older adults designated as requiring ALC should also be made aware of the importance of finding creative solutions to address missed opportunities for nursing care related to mobility and meaningful activity (Kalisch, 2006). Findings from the current study (possibly in story form) could be used to illustrate the importance of getting to know patients and their families in order to gain better insight into patient descriptions of their experience and insights that might arise out of this dialogue that could direct creative planning for meaningful activity (Nolan et al., 1995).

At the individual level, the findings of this study include stories about the experiences of older patients and family caregivers related to ALC. These stories could provide a useful and powerful teaching tool at all three levels described in the Glasby framework. At the level of the individual health professional, these stories about challenging life transitions of older adults might influence the attitudes and knowledge of undergraduate nursing students since programs in undergraduate nursing education have been slow to incorporate gerontological content and practice experience into their curricula (Holroyd, Dahlke, Fehr, Jung, & Hunter, 2009).

At the organizational level, senior administration and the Board of Directors of the hospital should be made aware of the finding of lack of mobility in this older adult population and its effects on patient deconditioning, loss of function, loss of independence and increased costs for older patients. Finally, at the structural level, the

stories about hospitalized older adults waiting for reunification with their spouse who is already placed in LTCH, and the unique financial dilemmas that they face, should be shared with senior administrators at the LHIN and MOHLTC. These findings could alert them to some of the problems and dilemmas that are created in the current legislation related to the LTCH placement process.

Implications for Research

The findings from the current study have important implications for research at the individual, organizational, and structural level. At the individual level, further research should explore: experiences of older patients with dementia who are designated as requiring ALC; uncertainty as part of the experience of ALC; patients and healthcare providers as characters in each other's stories; and knowledge of ALC among patients, family members, and healthcare providers. At the organizational level, research should further explore the implementation of strategies to better manage uncertainty associated with the experience of ALC. At the structural level, research should further explore the challenges faced by patients and families when level of placement needed is ambiguous.

At the individual level, further research should include the perspective of older patients with dementia on the experience of ALC since they are an important group impacted by the phenomenon of ALC. Neither the current study, given the problems encountered with recruiting family caregivers for the research, nor previous studies of experiences of ALC, have addressed this perspective. In general, the perspective of persons with dementia is not well represented in the research literature (Dewing, 2007).

Also at the individual level, the central finding of this study was that uncertainty is a key concern for patients and family caregivers in the midst of the ALC experience. Building on these insights, future research questions might seek deeper understanding of the phenomenon of uncertainty in the midst of the ALC experience. Such a study could be designed using a phenomenological qualitative approach in order to describe the essence of that experience (Creswell, 2007). In this case, the lived experiences of patients, family caregivers, and health professionals would be explored about their experience of uncertainty.

At the individual level, a novel component of this narrative study was its simultaneous examination of the experiences of patients and family caregivers in the midst of a common circumstance. The narratives resulting from this investigation presented each patient and family caregiver as "characters in each other's stories" (Frank, 2002). The findings in this study revealed interesting points of commonality and difference based on these perspectives. It would be informative to apply this same approach to examining the experiences of healthcare professionals in tandem with patients or family caregivers which might give direction in encouraging the kind of helpful dialogue that Frank ultimately advocates between health professionals and the people they serve.

Finally, at the individual level, future research questions might describe the state of knowledge about ALC for patients, family caregivers, and health professionals. For this purpose, a descriptive quantitative design using surveys of patients, family

caregivers, and health professionals would be appropriate. Survey items could in part be based on the findings of the current study.

At the organizational level, future research questions should evaluate the effectiveness of interventions intended to manage the uncertainty of the ALC experience using a randomized control trial design. Such interventions might be based on concepts related to the provision of information as described in Mishel's Uncertainty in Illness Theory and the ideas about support in the midst of existential uncertainty put forward by Penrod (2007).

At the structural level, a specific finding of this study was the unique uncertainty that patients like Teresa and Nancy and their families faced when assessments were still unclear about whether LTCH or Retirement Home was appropriate to their level of function. Further research at the regional and provincial level in this area would be helpful to clarify problems and needs related to this specific aspect of the ALC experience and begin to point toward what services might be needed in the hospital or community sector to better address the assessment needs of this group.

Limitations of This Study

This study has several limitations. Given the narrative framework and the intention to explore through in depth interviews the experiences of participants, the number of participants involved was small. This approach therefore limits the generalization of the findings. The study involved examination of the issue of ALC in only one acute care setting. Patients and family caregivers in different hospitals may have experiences which are very different than those of the participants in this study. This

study only included English speaking participants and therefore may not represent the experiences of many patients in this setting who do not speak English.

Unfortunately, no family caregivers or patients with servere dementia were recruited to the current study. This group of older adults is significantly impacted by the phenomenon of ALC, and the absence of their perspective, by proxy through family caregivers in this instance, limits a fuller understanding of the range of experiences related to ALC.

As previously described under Ethical Considerations, I approached the current study aware of my dual role in the hospital setting as a researcher and a clinician. At different points in the study process, I know that this dual role created dilemmas and challenges for me. I am not aware of any way in which this may have limited or compromised my interaction with participants. In terms of interpreting the findings of this study, my approach, consistent with narrative method, has been to seek transparency about the stories that I bring to this research. My status as employee at the hospital, however, may also have been a strength of the current study. Without my intimate knowledge of hospital processes, and my relationship with colleagues involved in the study, these study findings may not have been achieved.

While six of the seven narratives from the first interviews were confirmed with participants, in the end only 13 of 21 possible narrative summaries were reviewed by the participants. Many of the later narratives were not reviewed for reasons such as sudden, unexpected discharge and family caregiver participants not being available prior to discharge. The protocol for this study required that contact with patient and family

caregiver be discontinued after the patient was discharged from hospital, and therefore no procedure was used to check later re-storied narratives or interim field texts. An interesting discussion has recently been launched in the field of narrative inquiry concerning the interpretation of texts, the extent to which a participant owns a text emerging from an inquiry, and what weight should be placed on participants' opinion of the truth of a given interpretation of their experiences (Josselson, 2011). However, the method chosen for this inquiry clearly promotes the use of such approaches as an important part of the inquiry process and its relative lack in this instance is seen as a limitation of this study.

It may be challenging to know how best to apply the findings of this study given the changing nature of provincial policy. Many of the procedures at the hospital around ALC have changed over the course of the past year, even in the midst of the data collection period, and it is difficult to know how these policies will change in the coming months and years.

Conclusion

The findings of the current study have provided insight into the patient and family caregiver experience of ALC. The major finding was that *uncertainty* was a significant part of the experience of ALC for these participants. This uncertainty occurred across all three dimensions of experience described by Clandinin and Connelly (2000). In the personal dimension, patient participants spoke of uncertainty about their self-concept and described discontinuity between their past self-concept, their present self-concept in hospital while designated as requiring ALC, and the uncertain nature of their imagined

future self-concept or possible selves. In the dimensions of time and place, all participants described uncertainty related to waiting for placement and some of the struggles that followed from this. In the dimension of interactions with the hospital social and physical environment, participants provided in-depth descriptions of uncertainty they experienced related to not knowing about information and planning, not being included in planning for their future, lack of mobility, and lack of meaningful activity.

These findings have important implications for practice, policy, education, and future research, and recommendations in these areas were discussed in some detail. The ultimate objective of these recommendations is the creation of an environment which is more supportive of patients and families in the midst of a challenging and uncertain experience.

Narrative inquiry acknowledges the tentative nature of findings in any inquiry into human experience. As Clandinin and Connelly (2000) describe it, "The attitude in a narrative perspective is 'doing one's best' under the circumstance, knowing that other possibilities, other interpretations, other ways of explaining things are possible." This tentativeness has to do with the many particularities of a given inquiry given the nesting of stories that is understood to be part of the inquiry experience itself: beginning in the midst of the past and present stories that the participants and researcher bring to the moment of inquiry; acknowledging the findings of inquiry as a unique story reflecting the interaction of the ongoing stories of participants and researcher, at this time, in this setting; and finally, knowing that this time of inquiry reflects only a brief cross section of the larger continuity of participant experience that will continue long after completion of

the inquiry. In other words, the findings of any narrative inquiry are never the final word on a person's experience (Frank, 2004).

My reason for conducting this narrative study of experiences of ALC was ultimately rooted in my belief that the particular stories of older patients and family caregivers would motivate members of the healthcare community to seek effective solutions to the problem of ALC. From the perspective of the healthcare system, the implications of this problem are significant and complex, and solutions will surely need to be carefully informed and thoughtfully strategized in order to effectively address deficiencies in the systems of care for older adults which ALC is ultimately a symptom of. From the perspective of the patient and family, the implications are personal and profound. For them, this time in hospital while designated as requiring ALC represents a crucial transition in the older adult's life, and for many, like Bob, this experience will occur at the very end of their life. For them, there is no second chance to get it right.

REFERENCES

Alzheimer Society of Canada. (2010). *Rising tide: The impact of dementia on Canadian society - Executive summary.* Retrieved from Alzheimer Society of Canada http://www.alzheimer.ca/docs/RisingTide/Rising%20Tide_Full%20Report_Eng_FINAL_Secured%20version.pdf

Aronson, J. (2002). Elderly people's accounts of home care rationing: Missing voices in long-term care policy debates. *Ageing and Society, 22*, 399-418. doi:10.1017/S0144686X02008759

Aronson, J. (2006). Silenced complaints, suppressed expectations: The cumulative effects of home care rationing. *International Journal of Health Services, 36*, 535-556. doi:10.2190/CGPJ-PRWN-B1H6-YVJB

Atwal, A. (2002). Nurses' perceptions of discharge planning in acute health care: A case study in one British teaching hospital. *Journal of Advanced Nursing, 39*, 450-458. doi:10.1046/j.1365-2648.2002.02310.x

Bailey, D.E., Jr., Wallace, M., & Mishel, M. H. (2007). Watching, waiting and uncertainty in prostate cancer. *Journal of Clinical Nursing. 16*, 734-741. doi:10.1111/j.1365-2702.2005.01545.x

Bauer, M., Fitzgerald, L., Haesler, E., & Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A

review of the evidence. *Journal of Clinical Nursing, 18*, 2539-2546. doi:10.1111/j.1365-2702.2008.02685.x

Baumann, M., Evans, S., Perkins, M., Curtis, L., Netten, A., Fernandez, J. L., et al. (2007). Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge. *Health & Social Care in the Community, 15*, 295-305. doi:10.1111/j.1365-2524.2007.00697.x

Béland, F., Bergman, H., Lebel, P., Clarfield, A. M., Tousignant, P., Contandriopoulos, A.-P., et al. (2006). A system of integrated care for older persons with disabilities in Canada: Results from a randomized controlled trial. *Journals of Gerontology Series A: Biological Sciences & Medical Sciences, 61A*, 367-373. Retrieved from http://biomedgerontology.oxfordjournals.org/

Bronskill, S. E., Carter, M. W., Costa, A. P., Esensoy, A. V., Gill, S. S., Gruneir, A., et al. (2010). *Aging in Ontario: An ICES chartbook of health service use by older adults.* Retrieved from Institute of Clinical Evaluative Sciences .http://www.ices.on.ca/file/AAH%20Chartbook_interactive_final_Feb2010.pdf

Brown, C. J., Friedkin, R. J., & Inouye, S. K. (2004). Prevalence and outcomes of low mobility in hospitalized older patients. *Journal of the American Geriatrics Society, 52*, 1263-1270. doi: 10.1111/j.1532-5415.2004.52354.x

Bull, M. J., & Roberts, J. (2001). Components of a proper hospital discharge for elders. *Journal of Advanced Nursing, 35*, 571-581. doi: 10.1046/j.1365-2648.2001.01873.x

Butler-Jones, D. (2010). *The chief public health officer's report on the state of public health in Canada: Growing older - adding life to years.* Retrieved from Public Health Agency of Canada http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/pdf/cpho_report_2010_e.pdf

Callahan, E. H., Thomas, D. C., Goldhirsch, S. L., & Leipzig, R. M. (2002). Geriatric hospital medicine. *Medical Clinics of North America, 86*, 707-729. doi:10.1016/S0025-7125(02)00014-7

Callen, B. L., Mahoney, J. E., Grieves, C. B., Wells, T. J., & Enloe, M. (2004). Frequency of hallway ambulation by hospitalized older adults on medical units of an academic hospital. *Geriatric Nursing, 25*, 212-217. doi:10.1016/j.gerinurse.2004.06.016

Canada. The Senate. Special Senate Committee on Aging. (2009). Final report: *Canada's aging population: Seizing the opportunity.* Retrieved from Parliament of Canada http://www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf

Canadian Institute for Health Information. (2009). Alternate level of care in Canada. Retrieved from Canadian Institute for Health Information http://secure.cihi.ca/cihiweb/products/ALC_AIB_FINAL.pdf

Cancer Care Ontario. *Alternate level of care- Provincial ALC definition.* Retrieved February 20, 2010, from http://www.cancercare.on.ca/ocs/alc/

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly, 36*, 657-680. doi:10.1111/j.1533-8525.1995.tb00459.x

Clandinin, D. J., & Rosiek, J. (2007). Mapping a landscape of narrative inquiry: Borderland spaces and tensions. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 35-75). Thousand Oaks, CA: Sage.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.

Creswell, J. W. (2007). *Qualitative inquiry & research design : Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Denzin, N. K. (1989). *Interpretive interactionism*. Newbury Park, CA: Sage.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*, 11-25. doi:10.1177/1471301207075625

Disenfranchisement, n. In *Oxford English Dictionary* online dictionary. Retrieved August 27, 2011, from http://www.oed.com

Doleweerd, J., & Berezny, T. (2009). Having their say and choosing their way project: Catch 22: Report 2: People's experience going to long-term care after being hospitalized. Retrieved from http://www.changefoundation.ca/docs/HTSLTCHfinal.pdf

Driscoll, A. (2000). Managing post-discharge care at home: An analysis of patients' and their carers' perceptions of information received during their stay in hospital. *Journal of Advanced Nursing, 31*, 1165-1173. doi:10.1046/j.1365-2648.2000.01372.x

Efraimsson, E., Sandman, P.O., & Rasmussen, B. H. (2006). 'They were talking about me' - elderly women's experiences of taking part in a discharge planning conference. *Scandinavian Journal of Caring Sciences, 20*, 68-78. doi:10.1111/j.1471-6712.2006.00382.x

Fisher, S. R., Goodwin, J.S., Protas, E.J., Kuo, Y.-F., Graham, J.E., Ottenbacher, K.J., et al. (2011). Ambulatory activity of older adults hospitalized with acute medical illness. *Journal of the American Geriatrics Society, 59*, 91-95. doi:10.1111/j.1532-5415.2010.03202.x

Flacker, J., Park, W., & Sims, A. (2007). Hospital discharge information and older patients: Do they get what they need? *Journal of Hospital Medicine, 2*, 291-6. doi:10.1002/jhm.166

Forman, J., Creswell, J. W., Damschroder, L., Kowalski, C. P., & Krein, S. L. (2008). Qualitative research methods: Key features and insights gained from use in infection prevention research. *American Journal of Infection Control, 36*, 764-771. doi:10.1016/j.ajic.2008.03.010

Frank, A. W. (1995). *The wounded storyteller : Body, illness, and ethics*. Chicago ; University of Chicago Press.

Frank, A.W. (1998). Just listening: Narrative and deep illness. *Families, Systems & Health: The Journal of Collaborative Family Healthcare, 16*, 197-212. doi:10.1037/h0089849

Frank, A. W. (2002). "How can they act like that?": Clinicians and patients as characters in each other's stories. *Hastings Center Report, 32*(6), 14-22. Retrieved from http://www.jstor.org/stable/3528129

Frank, A.W. (2004). *The renewal of generosity: Illness, medicine, and how to live.* Chicago: University of Chicago Press.

Frketich, J. (2009, August 8). Under pressure: Hospitals need to clear beds for emergency patients, long-term care facilities don't have room, and families feel unable to care for their frail parents at home. how does a health-care system show compassion for the elderly? *The Hamilton Spectator,* pp. WR1, WR7.

Frketich, J. (2010, November 4). More RPNs at Hamilton hospitals: Numbers point to growing use of lower paid health care workers. *The Hamilton Spectator,* p. A6.

Glasby, J., & Littlechild, R. (2001). Professional issues. inappropriate hospital admissions: Patient participation in research. *British Journal of Nursing, 10*, 738-741. Retrieved from http://www.britishjournalofnursing.com/

Glasby, J. (2004). Discharging responsibilities? Delayed hospital discharges and the health and social care divide. *Journal of Social Policy, 33*, 593-604. doi:10.1017/S0047279404008013

Glasby, J., Littlechild, R., & Pryce, K. (2006). All dressed up but nowhere to go? Delayed hospital discharges and older people. *Journal of Health Services Research & Policy, 11*, 52-58. doi:10.1258/135581906775094208

Glasby, J., Martin, G., & Regen, E. (2008). Older people and the relationship between hospital services and intermediate care: Results from a national evaluation. *Journal of Interprofessional Care, 22*, 639-649. doi:10.1080/13561820802309729

Grimsbo, G. H., Finset, A., & Ruland, C. M. (2011). Left hanging in the air: Experiences of living with cancer as expressed through e-mail communications with oncology nurses. *Cancer Nursing, 34*, 107-116. doi:10.1097/NCC.0b013e3181eff008

Hellstrom, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*, 608-619. doi:10.1177/0969733007080206

Higgins, I., Joyce, T., Parker, V., Fitzgerald, M., & McMillan, M. (2007). The immediate needs of relatives during hospitalisation of acutely ill older relatives. *Contemporary Nurse : A Journal for the Australian Nursing Profession, 26*, 208-220. doi:10.5172/conu.2007.26.2.208

Holroyd, A., Dahlke, S., Fehr, C., Jung, P., & Hunter, A. (2009). Attitudes toward aging: Implications for a caring profession. *The Journal of Nursing Education, 48*, 374-380. doi:10.1111/j.1463-1318.2009.01951.x

Houghton, A., Bowling, A., Jones, I., & Clarke, K. (1996). Appropriateness of admission and the last 24 hours of hospital care in medical wards in an east London teaching group hospital. *International Journal for Quality in Health Care, 8*, 543-553. doi:10.1093/intqhc/8.6.543

Howlett, K. (2010, December 6). Needs of aging Canadians creating ER bottlenecks. *The Globe and Mail*, pp. A1, A6.

Howlett, K. (2011, July 10). Integrating health care necessary for an aging population. *The Globe and Mail.* Retrieved from http://www.theglobeandmail.com

Huber, D., & McClelland, E. (2003). Patient preferences and discharge planning transitions. *Journal of Professional Nursing, 19*, 204-210. doi:10.1016/S8755-7223(03)00071-1

Jack, B. W., Chetty, V. K., Anthony, D., Greenwald, J. L., Sanchez, G. M., Johnson, A. E., et al. (2009). A reengineered hospital discharge program to decrease rehospitalization: A randomized trial. *Annals of Internal Medicine, 150*, 178-87. Retrieved from http://www.annals.org

Josselson, R. (2011). "Bet you think this song is about you": Whose narrative is it in narrative research? *Narrative Works: Issues, Investigations, & Interventions, 1*(1), 33-51. Retrieved from http://journals.hil.unb.ca/index.php/NW/article/view/18472/19971

Kalisch, B. (2006). Missed nursing care - A qualitative study. *Journal of Nursing Care Quality, 21,* 306-313. Retrieved from http://journals.lww.com/jncqjournal/pages/default.aspx

Kirkpatrick, H. (2005). Moving on from homelessness: A narrative inquiry (Doctoral dissertation). Retrieved from Proquest Digital Dissertations (Proquest Document ID 305440150)

Kydd, A. (2008). The patient experience of being a delayed discharge. *Journal of Nursing Management, 16,* 121-126. doi:10.1111/j.1365-2834.2008.00848.x

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation.* Thousand Oaks, CA: Sage.

Makaryus, A. N., & Friedman, E. A. (2005). Patients' understanding of their treatment plans and diagnosis at discharge. *Mayo Clinic Proceedings, 80,* 991-4. doi:10.4065/80.8.991

Markus, H., & Nurius, P. (1986). Possible selves. *American Psychologist, 41*(9), 954-969. doi:10.1037/0003-066X.41.9.954

McKee, K. J., Harrison, G., & Lee, K. (1999). Activity, friendships and wellbeing in residential settings for older people. *Aging and Mental Health, 3*, 143-152. doi:10.1080/13607869956307

Mishel, M. H. (1988). Uncertainty in illness. *Journal of Nursing Scholarship, 20*, 225-232. doi:10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship, 22*, 256-262. doi:10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H., & Clayton, M. F. (2003). Theories of uncertainty in illness. In M. J. Smith, & P. R. Liehr (Eds.), *Middle range theory for nursing* (pp. 25-48). New York: Springer.

Mishel, M. H., Germino, B. B., Gil, K. M., Belyea, M., & Laney, I. C. (2005). Benefits from an uncertainty management intervention for African-American and caucasian older long-term breast cancer survivors. *Psycho-Oncology, 14*, 962-978. doi:10.1002/pon.909

Naylor, M. D., Brooten, D., Campbell, R., Jacobsen, B. S., Mezey, M. D., Pauly, M. V., et al. (1999). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *JAMA 281*, 613-620. doi:10.1001/jama.281.7.613

Nelson, A. M. (2008). Addressing the threat of evidence-based practice to qualitative inquiry through increasing attention to quality: A discussion paper. *International Journal of Nursing Studies, 45*, 316-322. doi:10.1016/j.ijnurstu.2007.01.012

Nolan, M., Grant, G., & Nolan, J. (1995). Busy doing nothing: Activity and interaction levels amongst differing populations of elderly patients. *Journal of Advanced Nursing, 22*, 528-538. doi:10.1111/j.1365-2648.1995.tb02589.x

Ollerenshaw, J. A., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry, 8*, 329-347. doi:10.1177/1077800400800300

Ontario Association of Community Care Access Centres, Ontario Association of Non-Profit Homes and Services for Seniors, Ontario Hospital Association, & Ontario Long-Term Care Association. (2006). *Alternate level of care - challenges and opportunities: A collaborative position paper.* Retrieved from Community Care Access Centre http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=72

Ontario Health Quality Council. (2010). *Quality monitor: Ontario health quality council 2010 report on Ontario's health system*. Retrieved from Health Quality Ontario http://www.ohqc.ca/pdfs/2010_report_-_english.pdf

Ontario Hospital Association. (2011). *Alternative level of care (ALC): OHA ALC survey results: January 2011*. Retrieved from Ontario Hospital Association

http://www.oha.com/CurrentIssues/Documents/OHA%20ALC%20Survey%20Results%20%28June%202011%29%20-%20at%20June%2023.pdf

Ontario. Expert Panel on Alternate Level of Care. (2006). Appropriate level of care: A patient flow, system integration and capacity solution: Report by the expert panel on alternate level of care. Retrieved from Ontario Community Support Association http://www.ocsa.on.ca/userfiles/alc_report_20070117.pdf

Ontario. Legislative Assembly of Ontario. Second Session, 39th Legislature. The Hon. D. Matthews, Minister of Health and Long-Term Care (2010). Bill 46: An Act Respecting the Care Provided by Health Care Organizations. Retrieved from Legislative Assembly of Ontario http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2326&isCurrent=false&ParlSessionID=

Ontario. Ministry of Health and Long-Term Care. (2011a). Results-based plan briefing book 2010-11. Retrieved from Ministry of Health and Long-Term Care http://www.health.gov.on.ca/en/public/publications/rbplan/rbplan10/rbplan2010.aspx

Ontario. Ministry of Health and Long-term Care. (2011b). Public information: Senior's care: Retirement homes. Retrieved from Ministry of Health and Long-Term Care website on August 28, 2011 http://www.health.gov.on.ca/english/public/program/ltc/14_retirement.html

Ontario. Ministry of Health and Long-term Care. (2011c). Public information: Senior's care: Long-term care homes. Retrieved from Ministry of Health and Long-Term Care website on August 28, 2011 http://www.health.gov.on.ca/english/public/program/ltc/15_facilities.html

Parsons-Suhl, K., Johnson, M. E., McCann, J. J., & Solberg, S. (2008). Losing one's memory in early Alzheimer's disease. *Qualitative Health Research, 18*, 31. doi:10.1177/1049732307308987

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia, 1*, 173. doi:10.1177/147130120200100205

Penrod, J. (2007). Living with uncertainty: Concept advancement. *Journal of Advanced Nursing, 57*(6), 658-667. doi:10.1111/j.1365-2648.2006.04008.x

Pinnegar, S., & Daynes, J. G. (2007). Locating narrative inquiry historically: Thematics in the turn to narrative. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 3-34). Thousand Oaks, CA: Sage.

Relinquishment, n. In *Oxford English Dictionary* online dictionary. Retrieved August 27, 2011, from http://www.oed.com

Rich, M. L., Suleski, C., Kidish, S., Niamo, L., Russel, C., Raney, B., et al. (1999). The PACE model: Description and impressions of a capitated model of long-term care for the elderly. *Care Management Journals, 1*, 62. Retrieved from http://www.springerpub.com/product/15210987#.TlkR8F04e7s

Riessman, C. K., & Speedy, J. (2007). Narrative inquiry in the psychotherapy professions: A critical review. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 426-456). Thousand Oaks, CA: Sage.

Roberts, K. (2002). Exploring participation: Older people on discharge from hospital. *Journal of Advanced Nursing, 40*, 413-420. doi:10.1046/j.1365-2648.2002.02389.x

Schwandt, T. A. (2007). *The Sage dictionary of qualitative inquiry* (3rd ed.). Thousand Oaks, CA: Sage.

Scott, H. (2000). Elderly patients: People not 'bed-blockers'. *British Journal of Nursing, 9*, 528. Retrieved from http://www.britishjournalofnursing.com/

Sherratt, C., Soteriou, T., & Evans, S. (2007). Ethical issues in social research involving people with dementia. *Dementia, 6*, 463-479. doi:10.1177/1471301207084365

Swinkels, A., & Mitchell, T. (2009). Delayed transfer from hospital to community settings: The older person's perspective. *Health and Social Care in the Community, 17*, 45-53. doi:10.1111/j.1365-2524.2008.00796.x

Victor, C. R., Healy, J., Thomas, A., & Seargeant, J. (2000). Older patients and delayed discharge from hospital. *Health & Social Care in the Community, 8*, 443-452. doi:10.1046/j.1365-2524.2000.00270.x

Wait Time Alliance. (2011). *Time out!: Report card on wait times in Canada.* . Retrieved from Wait Time Alliance http://www.waittimealliance.ca/media/2011reportcard/WTA2011-reportcard_e.pdf

Wilson, A., Richards, S., & Camosso-Stefinovic, J. (2007). Older people's satisfaction with intermediate care: A systematic review. *Reviews in Clinical Gerontology, 17*, 199. doi:10.1017/S0959259808002475

Wilson, P. (2010, November 19). So near, yet so far away. *The Spec.com.* Retrieved from http://www.thespec.com/living/article/277514--so-near-yet-so-far-away

Wolf, Z. R. (2003). Exploring the audit trail for qualitative investigations. *Nurse Educator, 28*, 175-178. Retrieved from http://journals.lww.com/nurseeducatoronline/pages/default.aspx

Zisberg, A., Shadmi, E., Sinoff, G., Gur-Yaish, N., Srulovici, E., & Admi, H. (2011). Low mobility during hospitalization and functional decline in older adults. *Journal of the American Geriatrics Society, 59*(2), 266-273. doi:10.1111/j.1532-5415.2010.03276.x

Appendix A

Patient Screening Documents

Patient Identification Page for the study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

NOTE: This information serves as a participant identifier and will not be read into the database. It will be stored in a separate area.

Date: _____ (dd/mm/yy)

Name of Patient: _____

Study ID: P_____

Initials of Recruiter: _____

Has patient identified a family caregiver who might participate in this study?

Yes ☐ No ☐

Family Caregiver Identification Page for the study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

NOTE: This information serves as a participant identifier and will not be read into the database. It will be stored in a separate area.

Date: _____ (dd/mm/yy)

Has patient been excluded from the study for reasons of cognitive impairment as described in section C of the Patient Screening Form?

Yes ☐ No ☐

Group A – Family caregiver of patient who has not been excluded for cognitive impairment

Name of family caregiver: _____Telephone number:_( )_____

Relationship to patient participant (P_____) is: _____

Group B – Family caregiver of patient who has been excluded for cognitive impairment

Name of family caregiver: _____Telephone number:_( )_____

Relationship to patient is: _____

Study ID: F_____

Patient Screening Form
(to be used by health professionals recruiting for this study when the patient and their family caregiver both qualify for the study)

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Date: _____ (dd/mm/yy)

A) Consider patient for inclusion if all answers to the following are Yes.
If any question is answered No, please stop screening.

1. Designated **ALC** within the past 30 days? Yes ☐ No ☐
   Date designated ALC _____(dd/mm/yy)
2. Age **75 years** or older? Yes ☐ No ☐
3. Speaks and understands English? Yes ☐ No ☐
4. Admitted from a private home/residence? Yes ☐ No ☐
   (i.e., not from LTCF, Retirement Home, CCCU, group home)
5. a) Is there is a high likelihood that application will be made to a longterm care facility, complex continuing care, facility or retirement home within the next 3 months?
   Yes ☐ No ☐
   b) If Yes, to which facility will application most likely be made?
   Longterm Care ☐ Complex Continuing Care ☐ Retirement Home ☐ Other ☐_____

B) If any answer to the following is Yes, stop screening and exclude patient:

1. Designated as **ALC Palliative OR ALC Rehab?** Yes ☐ No ☐
2. Current or past referral to **Palliative Care Team**? Yes ☐ No ☐
3. Not aware of probable plan for placement? Yes ☐ No ☐

C) If any answer to the following is Yes, stop screening and exclude patient.

1. Patient has a diagnosis of **severe dementia:** Yes ☐ No ☐
2. Patient has a current **delirium**: Yes ☐ No ☐
3. Family member has given **proxy consent** for a procedure: Yes ☐ No ☐
4. Under the order of the Public Guardian Yes ☐ No ☐

D) If patient is excluded under section C but meets all other inclusion and exclusion criteria, please use Family Caregiver Screening Form to assess for possible caregiver participation when patient is excluded for reasons of severe cognitive impairment.

Family Caregiver Screening Form

(to be used by Health Professionals recruiting for this study when the patient is EXCLUDED under section C of the Patient Screening Form)

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.
Date: _____ (dd/mm/yy)

A) Consider family caregiver for inclusion if all answers to the following are Yes. If any question is answered No, please stop screening.

1. Patient designated **ALC** within the past 30 days? Yes ☐ No ☐
   Date designated ALC _____(dd/mm/yy)
2. Patient age **75 years** or older? Yes ☐ No ☐
3. Family caregiver speaks and understands English? Yes ☐ No ☐
4. Patient admitted from a private home/residence? Yes ☐ No ☐
   (i.e., not from LTCF, Retirement Home, CCCU, group home)
5. a) Is there is a high likelihood that patient application will be made to a longterm care facility, complex continuing care, facility or retirement home within the next 3 months? Yes ☐ No ☐
   b) If Yes, to which facility will application most likely be made?

Longterm Care ☐ Complex Continuing Care ☐ Retirement Home ☐ Other ☐_____

B) If any answer to the following is Yes, stop screening and exclude family caregiver:

1. Patient designated as **ALC Palliative OR ALC Rehab** Yes ☐ No ☐
2. Patient has current or past referral to **Palliative Care Team**:Yes ☐ No ☐
3. Patient under the order of a **Public Guardian**: Yes ☐ No ☐

Information for Recruiters Regarding Screening of Patients

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

This study is being done to understand the experiences of hospitalized older patients and their family caregivers after the patient has been identified as requiring Alternate Level of Care. This study may help nurses and other health professionals to provide better care for other older patients and family caregivers in a similar situation.

Patients and family caregivers who agree to participate in the study will be asked to to participate in 1 to 3 interviews over the next few weeks. Each interview will take about 1 hour. These interviews will be recorded. After each interview, the recordings will be transcribed. At a later date, they will be provided with a copy of a summary of the previous interview(s) for their review and feedback.

Please use the attached Patient Screening Form to screen for patients who could be included in the study.

Please use the attached Family Caregiver Screening Form to screen for family caregivers who could be included in the study in the case where a patient has been excluded for reasons of cognitive impairment as indicated by the criteria in section C of the Patient Screening Form.

If the patient meets criteria for inclusion in the study (ie, meets all inclusion criteria and is not excluded), please:

1. Give the patient a Patient Information Letter
2. Explain the study and ask the patient if s/he would be willing to participate in the study.
3. Obtain the name and telephone number of a family caregiver who the patient feels may be willing to participate in this study.
4. Complete the Patient and Family Caregiver Identification Pages (except study ID)
5. ***Contact Greg Cressman. Leave a message at …***

If the patient meets criteria for inclusion and is excluded only for reasons of cognitive impairment as indicated by the criteria in section C of the Patient Screening Form, please follow these steps in the order listed. Please stop the process and destroy any documentation if the condition is not met in steps 2 or 3.

1. Complete Family Caregiver Screening Form.
2. IF the family caregiver meets criteria for inclusion, THEN contact the primary family caregiver as indicated in the patient chart using the Family Caregiver Recruitment Script.
3. IF the family caregiver is willing to participate, THEN obtain permission to give their telephone number to Greg Cressman.
4. Complete the Family Caregiver Identification Page (except study ID)
5. ***Contact Greg Cressman. Leave a message at …***

Please return ALL completed forms including those for patients who are screened but are not eligible for the study. Return forms to Greg Cressman.

Appendix B

Patient Recruitment Script

Patient Recruitment Script
(to be used by Health Professionals to recruit patients who qualify for the study)

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Hello.

Is this a convenient time to speak with you about a research study that is being conducted here at St. Joseph's Hospital?

> [If no]: When would be a good time to speak with you?
>
> [If willing to meet another time, arrange a time to meet. If not interested in hearing about study, end conversation and thank the patient].

[If yes]: I am contacting you to ask whether you would be interested in learning about a research study that is being done to better understand the experiences of hospitalized older patients and their family caregivers after the patient has been identified as requiring Alternate Level of Care. This study may help nurses and other health professionals to provide better care for other older patients and family caregivers in a similar situation.

The Principal Investigator for this study is Greg Cressman, a Master of Nursing student at McMaster University. Patients and family caregivers who agree to participate in the study will be asked to participate in 1 to 3 interviews over the next few weeks. Each interview will take about 1 hour. These interviews will be recorded.

Would you be willing to have Greg Cressman contact you in order explain the study in more detail? If you do speak with Greg and learn more about the study, you can decide not to participate in the study at that time.

> [If no]: Thank you for your time. Good bye. [end of conversation].

[If yes]: Here is a copy of the Information Letter for the study.

Thank-you for agreeing to speak with Greg Cressman. He will contact you sometime in the next week.

Appendix C

Family Caregiver Recruitment Script

Family Caregiver Recruitment Script
(to be used by Health Professionals recruiting for this study when the patient is excluded for reason of severe cognitive impairment)

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Hello.
My name is _____ and I am involved with the care of _____ (name of patient) here at St. Joseph's Hospital. The patient chart identifies you as the Substitute Decision Maker for _____ (name of patient). Is this a convenient time to speak with you about a research study that is being conducted here at St. Joseph's Hospital?

[If no]: When would be a good time to speak with you?
[If willing, set another time to meet. If not interested in hearing about study, end conversation and thank the family caregiver].

[If yes]: I am contacting you to ask whether you would be interested in learning about a research study that is being done to better understand the experiences of hospitalized older patients and their family caregivers after the patient has been identified as requiring Alternate Level of Care. This study may help nurses and other health professionals to provide better care for other older patients and family caregivers in a similar situation. The patient, your family member, will not be asked to participate in this study.

The Principal Investigator for this study is Greg Cressman, a Master of Nursing student at McMaster University. Family caregivers who agree to participate in the study will be asked to participate in 1 to 3 interviews over the next few weeks. Each interview will take about 1 hour. These interviews will be recorded.

Would you be willing to have Greg Cressman contact you in order explain the study in more detail? If you do speak with Greg and learn more about the study, you can decide not to participate in the study at that time.

[If no]: Thank you for your time. Good bye. [end of conversation].

[If yes]: Here is a copy of the Information Letter for the study.

What telephone number could Greg use to call you? _____ (record TP number).
What is a good time for him to call? _____ (record suggested times).

Thank-you for agreeing to speak with Greg Cressman. He will call you sometime in the next week.

Appendix D

Patient Information Letter

Title of Study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.
Financial support: Some of Greg Cressman's time is supported by [Hospital]. Cost of data analysis will be supported by a scholarship from the de Souza Institute.

INVITATION TO PARTICIPATE IN RESEARCH
You are invited to participate in this study because you are an older patient who has been identified as medically stable and requiring Alternate Level of Care. This study is the project of Greg Cressman, a Master of Nursing student at McMaster University. He will be supervised by Dr. Jenny Ploeg, also at McMaster University, and Dr. Anne Woods at St. Joseph's Healthcare Hamilton. You can choose to participate in the study or not. Your choice will not affect your care now or in the future.
WHY IS THIS STUDY BEING DONE?
This study is being done to understand the experiences of hospitalized older patients and their family caregivers after the patient has been identified as requiring Alternate Level of Care. This study may help nurses and other health professionals to provide better care for other older patients and family caregivers in a similar situation.
WHAT AM I BEING ASKED TO DO?
You are being asked to participate in 1 to 3 interviews here at the hospital over the next few weeks. Each interview will take about 1 hour. These interviews will be audio recorded. Every effort will be made to ensure privacy for the interviews. However, it is possible that an interview will occur in your hospital bedroom which is shared with another patient and that some of what we discuss may be heard by others who are in the room at the time. This could include discussion we might have about your family and your life before coming to hospital. You can share only what you feel comfortable sharing. After each interview, the recordings will be transcribed. At a later date, you will be provided with a copy of a summary of the previous interview(s) for your review and feedback.
ARE THERE ANY RISKS?
You will be asked questions to try to understand your experience of your recent illness and stay in hospital. They are not designed to cause any discomfort. You do not have to discuss anything you do not want to discuss. If a question causes any discomfort, you can choose not to answer it.
ARE THERE ANY BENEFITS?
Participation in this research provides an opportunity for you to tell your story and to think about your experiences. The information which comes from this study may benefit

other patients and family caregivers in the future who are in a similar situation. You will be offered a copy of a report about this study when it is complete.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study. If you do choose to participate you will be offered a gift certificate worth $10.00 for the Second Cup or the St. Joseph's Hospital Gift and Flower Shop.

WILL THERE BE ANY COSTS TO ME IN THIS STUDY?

Parking expenses for participating family members will be reimbursed. There are no other anticipated costs to you.

WHAT WILL HAPPEN TO MY PERSONAL INFORMATION?

All identifying information, and the interview recordings and transcripts. will remain confidential.

This study will collect your name, your age, and the name and telephone number of your family caregiver. This information will be kept separate from any interview information which will be identified only with a study number. The only person who will have access to both your name and interview information will be Greg Cressman. The thesis supervisor and thesis committee for Greg Cressman will listen to interview recordings and read transcripts but will not know who you are. The information will be stored on a password protected computer file and in locked filing cabinets at St. Joseph's Hospital. This will be kept for 10 years, and then destroyed. At no time will your story or what you have said be identified by name in the study.

CAN PARTICIPATION END EARLY?

You may withdraw from this study at any time. You may stop an interview at any time, or you may choose to answer only certain questions. If you wish to withdraw, contact Greg Cressman using the telephone number provided at the end of this letter. If there is any new information about the study that arises after this, you will be informed and given the opportunity to decide whether to continue. If you do withdraw, you will be asked whether or not you give permission to use the information and interviews collected to that point in time.

IF I HAVE QUESTIONS ABOUT THIS STUDY, WHO SHOULD I CALL?

If you have questions about this study, please contact Greg Cressman at telephone number 905-525-9140 Ext. 22294 or Dr. Jenny Ploeg at 905-525-9140 Ext.22294. This study has been reviewed by the SJHH Research Ethics Board (REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, SJHH REB at 905.522.1155 x 33537

This letter is for you to keep.

Appendix E

Telephone Script for Family Caregiver Contact - A

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Hello.

My name is Greg Cressman and I am a Master of Nursing student at McMaster University. I received your name from your family member _____ [Name] who has agreed to participate in this study and suggested that you might also be willing to participate. Is this a convenient time to speak with you about this study?

[If no]: When would be a good time to call? Thank you. Good bye. [End of call]

[If yes]: I am conducting a study called Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care. I am interested in the stories of hospitalized older patients and their family caregivers after the patient has been identified as medically stable or requiring Alternate Level of Care. What is the experience? This study will help nurses and other health professionals to provide better care for other older patients and families in a similar circumstance.

This study will involve 5 to 8 family caregivers. You are being asked to participate in 1 to 3 interviews here at the hospital or another location of your choice over the next few weeks. Each interview will last about 1 hour. These interviews will be audio recorded. After each interview, the recordings will be transcribed. At a later date, you will be provided with a copy of a summary of the previous interview(s) for your review and feedback.

Are you willing to meet with me to discuss the study further?

[If no]: Thank you for your time. Good bye. [end of call]

[If yes]:Let's arrange a place and time to meet.

Would it be convenient for you to meet sometime at the hospital when you are visiting your family member _____ [Name]?

[If yes, make arrangement for a time to meet at the hospital]

[If more convenient somewhere else]: What place would be convenient for you to meet? [Note address]

When are you available? [Note date and time]

Thank you for agreeing to participate in this study. I'll see you at _____ [time], on _____ (date) at _____ (location).

I'll call you the day before to make sure that this time is still convenient for you.

Thank you. Good-bye. [End of call]

Appendix F

Telephone Script for Family Caregiver Contact – B

(to be used by the Principal Investigator when contacting the family caregiver of a patient who is excluded from the study for reason of severe cognitive impairment)

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Hello.
My name is Greg Cressman and I am a Master of Nursing student at McMaster University. I received your name from the health care team caring for your family member _____ [name of patient]. This person identified you as the Substitute Decision Maker for _____ [name of patient]. Is this a convenient time to speak with you about a research study being conducted at St. Joseph's Hospital Hamilton?

[If no]: When would be a good time to call? Thank you. Good bye. [End of call]

[If yes]: I am conducting a study called Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care. I am interested in the stories of hospitalized older patients and their family caregivers after the patient has been identified as medically stable or requiring Alternate Level of Care. What is the experience? This study will help nurses and other health professionals to provide better care for other older patients and families in a similar circumstance. Your family member _____ [name of patient] will not be asked to participate in this study.

You are being asked to participate in 1 to 3 interviews here at the hospital or another location of your choice over the next few weeks. Each interview will last about 1 hour. These interviews will be audio recorded. After each interview, the recordings will be transcribed. At a later date, you will be provided with a copy of a summary of the previous interview(s) for your review and feedback.

Are you willing to meet with me to discuss the study further?

[If no]: Thank you for your time. Good bye. [end of call]

[If yes]:Let's arrange a place and time to meet.

Would it be convenient for you to meet sometime at the hospital when you are visiting your family member _____ [Name]?

[If yes, make arrangement for a time to meet at the hospital]

[If more convenient somewhere else]: What place would be convenient for you to meet?

[Note address]

When are you available? [Note date and time]

Thank you for agreeing to participate in this study. I'll see you at _____ [time], on

_____ (date) at _____ (location).

I'll call you the day before to make sure that this time is still convenient for you.

Thank you. Good-bye. [End of call]

Appendix G

Patient Consent Form

Title of Study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.
Financial support: Some of Greg Cressman's time is supported by St. Joseph's Healthcare Hamilton. Cost of data analysis will be supported by a scholarship from the de Souza Institute.
.

Participant:
I have read the information letter. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name Signature Date

Person obtaining consent:
I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study Signature Date

Witness: (required if participant unable to read)
I was present when the information in this form was explained and discussed with the participant. I believe the participant understands what is involved in this study.

Name Signature Date

Appendix H

Patient Biographical Information

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Study ID: P_____

Age: _____

Sex: Male ☐ Female ☐

Marital Status: Married ☐ Divorced ☐
Widowed ☐ Common-law ☐
Separated ☐ Single/Never Married ☐

Who else lives with you (check all that apply)?
Spouse ☐ Sister ☐ Brother ☐ Child/ren ☐ Grandchild/ren ☐
Niece ☐ Nephew☐ Other☐_____

Total number in the household including yourself _____

How are you related to the family caregiver you suggested for this study? He/she is your:
Spouse ☐ Sister ☐ Brother ☐ Child/ren ☐ Grandchild/ren ☐
Niece ☐ Nephew☐ Other☐_____

Education Level (check √ highest level completed):
Less than Grade 8 ☐ Completed Grade 8 ☐
Some high school☐ Completed high school ☐
Some college ☐ Completed college ☐
Some university☐ Completed university ☐
Masters or PhD☐ Other ☐ _____

Appendix I

Family Caregiver Information Letter

Title of Study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.
Financial support: Some of Greg Cressman's time is supported by [hopstial]. Cost of data analysis will be supported by a scholarship from the de Souza Institute.

INVITATION TO PARTICIPATE IN RESEARCH

You are invited to participate in this study because you are a family caregiver of an older patient who has been identified as medically stable and requiring Alternate Level of Care. This study is the project of Greg Cressman, a Master of Nursing student at McMaster University. He will be supervised by Dr. Jenny Ploeg, also at McMaster University, and Dr. Anne Woods at St. Joseph's Healthcare Hamilton. You can choose to participate in the study or not. Your choice will not affect your care now or in the future.

WHY IS THIS STUDY BEING DONE?

This study is being done to understand the experiences of hospitalized older patients and their family caregivers after the patient has been identified as requiring Alternate Level of Care. This study may help nurses and other health professionals to provide better care for other older patients and family caregivers in a similar situation.

WHAT AM I BEING ASKED TO DO?

You are being asked to participate in 1 to 3 interviews over the next few weeks. Each interview will take about 1 hour. These interviews will be audio recorded. After each interview, the recordings will be transcribed. At a later date, you will be provided with a copy of a summary of the previous interview(s) for your review and feedback.

ARE THERE ANY RISKS?

You will be asked questions to try to understand your experience of your family member's illness and stay in hospital. They are not designed to cause any discomfort. You do not have to discuss anything you do not want to discuss. If a question causes any discomfort, you can choose not to answer it.

ARE THERE ANY BENEFITS?

Participation in this research provides an opportunity for you to tell your story and to think about your experiences. The information which comes from this study may benefit other patients and family caregivers in the future who are in a similar situation. You will be offered a copy of a report about this study when it is complete.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study. If you do choose to participate you will be offered a gift certificate worth $10.00 for the Second Cup or the St. Joseph's Hospital Gift and Flower Shop.

WILL THERE BE ANY COSTS TO ME IN THIS STUDY?

Parking expenses for participating family caregivers will be reimbursed. There are no other anticipated costs to you.

WHAT WILL HAPPEN TO MY PERSONAL INFORMATION?

All identifying information, and the interview recordings and transcripts. will remain confidential.

This study will collect your name and telephone number. This information will be kept separate from any interview information which will be identified only with a study number. The only person who will have access to both your name and interview information will be Greg Cressman. The thesis supervisor and thesis committee for Greg Cressman will listen to interview recordings and read transcripts but will not know who you are. The information will be stored on a password protected computer file and in locked filing cabinets at St. Joseph's Hospital. This will be kept for 10 years, and then destroyed. At no time will your story or what you have said be identified by name in the study.

CAN PARTICIPATION END EARLY?

You may withdraw from this study at any time. You may stop an interview at any time, or you may choose to answer only certain questions. If you wish to withdraw, contact Greg Cressman using the telephone number provided at the end of this letter. If there is any new information about the study that arises after this, you will be informed and given the opportunity to decide whether to continue. If you do withdraw, you will be asked whether or not you give permission to use the information and interviews collected to that point in time.

IF I HAVE QUESTIONS ABOUT THIS STUDY, WHO SHOULD I CALL?

If you have questions about this study, please contact Greg Cressman at telephone number 905-525-9140 Ext. 22294 or Dr. Jenny Ploeg at 905-525-9140 Ext.22294.

This study has been reviewed by the SJHH Research Ethics Board (REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, SJHH REB at 905.522.1155 x 33537

This letter is for you to keep.

Appendix J

Family Caregiver Consent Form

Title of Study:
Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.
Financial support: Some of Greg Cressman's time is supported by St. Joseph's Healthcare Hamilton. Cost of data analysis will be supported by a scholarship from the de Souza Institute.

.
Participant:
I have read the information letter. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name Signature Date

Person obtaining consent:
I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study Signature Date

Witness: (required if participant unable to read)
I was present when the information in this form was explained and discussed with the participant. I believe the participant understands what is involved in this study.

Name Signature Date

Appendix K

Family Caregiver Biographical Information

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care

Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Study ID: F_____

Age: _____

Sex: Male ☐ Female ☐

Marital Status: Married ☐ Divorced ☐
Widowed ☐ Common-law ☐
Separated ☐ Single/Never Married ☐

Who else lives with you?
Spouse ☐ Sister ☐ Brother ☐ Child/ren ☐ Grandchild/ren ☐
Niece ☐ Nephew☐ Other☐_____

Total number in the household including yourself: _____

How are you related to the patient? He/she is your:
Spouse ☐ Sister ☐ Brother ☐ Child/ren ☐ Grandchild/ren ☐
Niece ☐ Nephew☐ Other☐_____

Education Level (check √ highest level completed):
Less than Grade 8 ☐ Completed Grade 8 ☐
Some high school☐ Completed high school ☐
Some college ☐ Completed college ☐
Some university☐ Completed university ☐
Masters or PhD☐ Other ☐ _____

Appendix L

Patient Interview Guide

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Introductory Statement

Thank-you for agreeing to be interviewed.
This research looks at experiences which you have had during your hospital stay. I am particularly interested in your experiences since your health care team decided that you are medically stable and began making plans with you for leaving the hospital. This is also known as being identified as requiring Alternate Level of Care.
I will be audio recording our interview. You may ask me to stop the recorder at any time. You may choose not to answer certain questions. There are no "right" or "wrong" answers. Your answers are confidential. Only my research committee and I will listen to the recordings and read your responses. Only I, however, will know who you are. I will also contact you at a later time to ask further questions about the information I will collect today.
Do you have any questions?
I will now turn the recorder on and start the interview.
[Note: Please see the Biographical Information Form for other questions which are asked of participants]

Preamble to interview Questions

The interview today should take about one hour. I would like you to speak about your more recent experiences in hospital, specifically since your health care team decided that you are medically stable and began making plans with you for leaving the hospital. However, I'd like to begin by spending a few minutes hearing about your life before you came to hospital. I have a number of questions which I would like to ask you and so I will keep track of the time and try to move from one question to the next so that we finish in about an hour.

Main Interview Questions (with bulleted suggestions for prompts)

1. Tell me about your life before you came to hospital.
   - Where were you living***?***
   - Were you receiving any supports? If yes, what?
   - Why did you come to hospital?
2. Tell me about your experiences while staying in the hospital.
   - Tell me about the early part of your hospital stay.
   - Tell me about your hospital stay more recently.
3. I understand that your health care team in the hospital has decided that you are medically stable and began making plans with you for discharge and for

leaving the hospital. This is also known as being identified as requiring Alternate Level of Care. How was this change in your hospital stay explained to you?

- What did you understand this to mean at that time?
- Did you have any questions about this? If yes, please describe.
- How well were your questions answered?
- Tell me about any discussions you have had with your health care providers about discharge or planning to leave the hospital.
- Who spoke to you?
- What did they say?
- What was it like for you?
- What do you understand this to mean now?
- What is your understanding of the present plan for your stay in hospital?

4. Tell me about your experiences in hospital since_____ (date) when you were identified as _____ [use terminology used by participant OR the phrase "medically stable'] or requiring Alternate Level of Care.

- Has anything changed since you were identified as _____[Participant Wording for requiring ALC]?
- How has it affected you?
- Tell me about your experiences in hospital right now.
- What is good about your experience in hospital?
- What could be better about your experience in hospital? How?
- What have you been feeling about your hospital experience?

5. Tell me about your plans after this hospital stay.

- What are your hopes for the future?
- What do you fear or worry about?

Conclusion

6. Now that you have come this far in your hospital stay, what suggestions might you give staff to improve the experience of patients who are identified as _____[Participant Wording for ALC]?
7. Is there anything else you would like to say?
8. Is there anything else I should have asked you?

Thank-you for participating in this interview.

If you would like to receive a copy of the final report for this study, please provide an email address or a mailing address.

Name: _____

Email Address: _____

Mailing Address: _____

_____

_____

Note: This form will be detached from the interview guide, will not be labeled with the study code, and will be stored in a secure location.

Appendix M

Family Caregiver Interview Guide

Title of Study: Experiences of Hospitalized Older Patients and Family Caregivers after the Patient is Designated as Requiring Alternate Level of Care
Principal Investigator: Greg Cressman, RN, MSc, (Nursing) (Student), McMaster University.

Introductory Statement

Thank-you for agreeing to be interviewed.
This research looks at experiences which you have had during your family member's hospital stay. I am particularly interested in your experiences since the health care team decided that your family member is medically stable and began making plans for her/him to leave the hospital. This is also known as being identified as requiring Alternate Level of Care.
I will be audio recording our interview. You may ask me to stop the recorder at any time. You may choose not to answer certain questions. There are no "right" or "wrong" answers. Your answers are confidential. Only my research committee and I will listen to the recordings and read your responses. Only I, however, will know who you are. I will also contact you at a later time to ask further questions about the information I will collect today.
Do you have any questions?
I will now turn the recorder on and start the interview.
[Note: Please see the Biographical Information Form for other questions which are asked of participants]

Preamble to Interview Questions

The interview today should take about one hour. I would like you to speak about your more recent experiences related to your family member's hospitalization, specifically since the health care team decided that she/he is medically stable and began making plans for her/him to leave hospital.
However, I'd like to begin by spending a few minutes hearing about your family member's life before she/he came to hospital. I have a number of questions which I would like to ask you and so I will keep track of the time and try to move from one question to the next so that we finish in about an hour.

Main Interview Questions (with bulleted suggestions for prompts)

1. Tell me about your family member's life before s/he came to hospital.
    a. Where was s/he living***?***
    b. Was s/he receiving any supports? If yes, what?
    c. Why did s/he come to hospital?
2. Tell me about your experiences during your family member's hospital stay.
    - Tell me about your experiences during the early part of her/his hospital stay.
    - Tell me about your experiences more recently.

3. I understand that the health care team has decided that your family member is medically stable and began making plans with him/her for discharge and for leaving the hospital. This is also known as being identified as requiring Alternate Level of Care. How was this change in your family member's hospital stay explained to you?
    - What did you understand this to mean at that time?
    - Did you have any questions about this? If yes, please describe.
    - How well were your questions answered?
    - Tell me about any discussions you have had with health care providers about your family member's discharge or plans to leave the hospital.
    - Who spoke to you?
    - What did they say?
    - What was it like for you?
    - What do you understand this to mean now?
    - What is your understanding of the present plan for your family member's stay in hospital?
4. Tell me about your experiences since_____ (date) when your family member was identified as _____ [use terminology used by participant OR the phrase "medically stable'] or requiring Alternate Level of Care.
    a. Has anything changed since your family member was identified as _____[Participant Wording for requiring ALC]?
    b. How has it affected you?
    c. Tell me about your experiences of your family member's hospitalization right now.
    d. What is good about your experience of your family member's hospitalization now?
    e. What could be better about your experience of your family member's hospitalization? How?
    f. What have you been feeling about your your family member's hospitalization?
5. Tell me about your family member's plans after this hospital stay.
    - What are your hopes for the future?
    - What do you fear or worry about?

Conclusion

6. Now that you have come this far in your family member's hospital stay, what suggestions might you give staff to improve the experience of family members and patients who are identified as _____[Participant Wording for requiring ALC]?
7. Is there anything else you would like to say?
8. Is there anything else I should have asked you?

Thank-you for participating in this interview.

If you would like to receive a copy of the final report for this study, please provide an email address or a mailing address.

Name: _____

Email Address: _____

Mailing Address: _____

_____

_____

Note: This form will be detached from the interview guide, will not be labeled with the study code, and will be stored in a secure location.

Appendix N

Five Stories: Patient and Family Caregiver Participants

Dan and His Daughter Sarah

Dan, early 80's, married, the first patient enrolled.

- lived at his own house with his wife (who has severe dementia) and daughter
- designated as requiring ALC 9 days after admission
- participated in 3 interviews on ALC days 32, 44, and 67 (day of discharge)
- all interviews occurred on the ALC Ward.

Sarah, one of two daughters, was single, in her late forties

- participated in two interviews on days 37 and 67 of Dan's ALC stay
- first interview was on the ALC Ward, the second was at McDonald's restaurant on day of discharge.

Teresa and her niece, Janice.

Teresa, late eighties, single

- lived alone in her own house
- designated as requiring ALC 11 days after admission
- participated in four interviews on ALC days 32, 46, 67, and 85 (day of discharge)
- all interviews occurred on the ALC Ward.
- Teresa's stay in hospital following ALC designation was the longest (12 weeks) in the study and her involvement (8 weeks) was also the longest.

Janice, single, in her fifties,

- participated in two interviews on the ALC Ward on days 37 and 60 of Teresa's ALC stay.

Bob and his son, Alan.

Bob, early eighties, married,

- lived alone in his own house
- his wife, also in her eighties, had severe dementia and was living in a LTCH to which Bob had also made an application 15 months before
- designated as requiring ALC 17 days after admission
- participated in 3 interviews on ALC days 18, 32, and 40 (2 days before discharge)
- first interview on Cardiac Ward, second and third on Flex Ward

Alan, married, was Bob's only child. Alan lived in the same city with Bob but spent week days at his work in a distant city.

- He participated in one interview on the Flex Ward on day 30 of Bob's ALC stay.

Nancy and her daughter, Barb.

Nancy, late eighties, a widow for almost 30 years,

- lived alone in her own house
- designated as requiring ALC 7 days after admission
- participated in 2 interviews on ALC days 19 and 31 (4 days before discharge)
- first interview on Flex Ward, second on ALC Ward

Barb, one of two daughters, lived in a different city about 45 minutes drive away.

- participated in 3 interviews on days 20, 32, and 35 of Nancy's ALC stay
- first two interviews were on Flex Ward, last interview at coffee shop in hospital entrance

Frank.

Frank, mid eighties, married,

- lived in a rented apartment with his wife who had dementia
- designated as requiring ALC 19 days after admission
- participated in 1 interview on ALC day 8 (three days before discharge).

His daughter declined to participate in the study.