

**WAITING FOR HOME:  
DEMENTIA AND THE ALTERNATE LEVEL OF CARE EXPERIENCE**

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

The Faculty of Graduate and Postdoctoral Studies

(Nursing)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

December 2020

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Waiting for Home: Dementia and the Alternate Level of Care Experience

submitted by Mariko Liette Sakamoto in partial fulfillment of the requirements for

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## **Abstract**

Patients who remain in hospital once their health has stabilized are designated Alternate Level of Care (ALC). This often occurs for patients living with dementia when care needs exceed what can be managed at home. Overall, ALC patients living with dementia experience lengthy hospitalizations. Unfortunately, there is little research that takes into account the experiences and needs of these patients. This Interpretive Description study, theoretically grounded in personhood and social citizenship perspectives, focused on the patients' experiences to address this gap in research and to better understand how care for ALC patients living with dementia can be improved.

Twenty-one individuals participated in this study: eight patient participants designated ALC living with dementia, six family members, and seven nurses. Data collection methods comprised of participant observations and general observations of the study setting, including patient rounds and meetings, totaling 106 hours of observations. Fourteen semi-structured interviews were conducted with family member and nurse participants, and with one patient participant. Informal conversations were undertaken with patient participants who did take part in interviews.

Findings from this study are presented in three parts, and include a selection of found poems. Firstly, the daily life of ALC patients living with dementia is explored, revealing the challenges the patients regularly encountered over long hospitalizations. Secondly, the distress that the patients experienced on a recurring basis is brought into sharp relief. Thirdly, the agency and resiliency of the patients is brought to the fore, widening the lens from which patients living with dementia can be considered. Findings are discussed in the context of the ambiguity of ALC

care, the pervasive liminality the patients experienced, and prevailing discourses around the behavioural and psychological symptoms of dementia.

Implications for nursing practice include the need to acknowledge and foster the abilities of patients living with dementia. The behaviour narrative and labeling prevalent in hospitals must also be challenged. Lastly, nurses need to recognize the significant transition that is the ALC experience. This study advocates for person-centered and inclusive nursing care, where ongoing needs are recognized and addressed, particularly for ALC patients living with dementia who are waiting for home.

## **Lay Summary**

Patients who stay in hospital once their health has stabilized are designated Alternate Level of Care (ALC). Overall, more can be done to improve these patients' care. There is little research focusing on ALC patients' care experiences, particularly for ALC patients living with dementia. This qualitative study utilized observations, informal conversations and interviews to address this gap in research, and in doing so, provide knowledge on how to improve nursing care for ALC patients living with dementia. Findings from this study show that hospitalization is difficult and distressing for ALC patients living with dementia. Despite these difficulties, the patients are resilient individuals with agency and specific needs that need to be recognized. This research shows that nurses need to provide care for ALC patients living with dementia in an inclusive manner where the patients' ongoing needs are recognized and addressed.

## **Preface**

This dissertation is the original, unpublished, and independent work of the author, M. Sakamoto. The illustrations and poems that have been included are the original work of the author. The research described in this dissertation was approved by the UBC Behavioral Ethics Board (H18-03337) and the Vancouver Coastal Health Research Institute (V18-03337).

I developed this research project, with support from my supervisor and dissertation committee. I independently conducted all of the field work, including interviews and observations. I also analyzed the data and wrote the initial draft of this dissertation. The supervisory committee provided guidance on data analysis, as well as critical review of the written work.

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## Abbreviations

<b>ABF</b>	Activity Based Funding
<b>ALC</b>	Alternate Level of Care
<b>ACE</b>	Acute Care for Elders
<b>BPSD</b>	Behavioural and Psychological Symptoms of Dementia
<b>CIHI</b>	Canadian Institute of Health Information
<b>DAD</b>	Discharge Abstract Database
<b>FN</b>	Field Note
<b>GPA</b>	Gentle Persuasive Approach
<b>ICD</b>	International Classification of Diseases
<b>ID</b>	Interpretive Description
<b>IPA</b>	International Psychogeriatric Association
<b>LLOS</b>	Long Length of Stay
<b>LPN</b>	Licensed Practical Nurse
<b>MAR</b>	Medication Administration Record
<b>NHF</b>	No Home First
<b>PO</b>	Per Os (by mouth)
<b>RN</b>	Registered Nurse
<b>PCC</b>	Patient Care Coordinator
<b>SNF</b>	Skilled Nursing Facility
<b>TED</b>	Thrombo-Embolus Deterrent
<b>TN</b>	Transition Nurse
<b>TST</b>	Transition Services Team
<b>UTI</b>	Urinary Tract Infection

## Glossary

<b>Advanced Dementia</b>	A term used throughout this dissertation to describe living with dementia when individuals require considerable supports to manage activities of daily living. This includes recognizing that individuals may experience difficulties with communication, as well as recognition that they may be quite far along on the trajectory of living with dementia.
<b>Alternate Level of Care</b>	A Canadian-specific designation for hospitalized patients who have completed the acute phase of their hospitalization but who cannot be discharged home. Many of these patients are waiting for a care home bed.
<b>Broda Chair</b>	A specialized geriatric chair, often equipped with a fitted tray. Also known as a Geri-chair.
<b>Home First</b>	A term used for plans that focus on discharging hospitalized patients home with services that will support them until a care home bed becomes available.
<b>Long Length of Stay</b>	A designation for patients whose hospital stay has exceeded 15 days.
<b>Transition Nurse</b>	A position held by a registered nurse in the hospital setting. Transition nurses are involved in discharge planning for patients who will require home health services, such as home care nursing or case management.

## **Acknowledgements**

I can only begin by acknowledging and thanking the patient participants who shared their experiences, time, personal space and stories with me. I am forever touched and changed by the time I spent with all of you and by what I learned from you. A sincere and deep thank you also to the family members and nurses who took the time to speak with me, and participated in interviews. I am also grateful to the staff and leadership team at the hospital setting where this research took place, where I was welcomed and encouraged to undertake this work.

I must foremost acknowledge and thank my supervisor and mentor Dr. Alison Phinney, whose support and guidance I could always count on. Alison, thank you for always answering all my emails and for all your feedback and encouragement over the years! Thank you also to my committee members, Dr. Jennifer Baumbusch and Dr. Genevieve Thompson for your expertise, support and insight. I am also so appreciative to Dr. Wendy Hall for her mentorship, and to Dr. Sally Thorne for her guidance on using Interpretive Description. Furthermore, I am grateful for funding and support from The University of British Columbia, The UBC School of Nursing, The Canadian Frailty Network and The Canadian Nurses Foundation.

The path to completing a PhD is not only made possible by the guidance and support of the experts a student gets to work with, but also by the friendships that are forged and strengthened during this period of time. Thank you to all my PhD friends, in particular my fellow UBC School of Nursing student colleagues: Courtney, Amel, Elizabeth, Christine, Melissa, Catherine and Max. A special thank you to my friend Dr. Jennifer Jackson and to “Alison’s Dinner Group”: Dr. Lillian Hung, Dr. Shelley Canning and particularly Dr. Gloria Puurveen (for all of our coffee and chat sessions). Thank you also to my friend Tracy Leroux whose interest and support in this project meant so much to me and who provided important and helpful

feedback on my writing. I am grateful for Monica Swanson for her wisdom, and a big thank you to Paulina Malcolm for helping me with my ethics application. I want to also mention my master's supervisor, mentor and friend Dr. Sharon Moore, who has continued to support and encourage me during this most recent academic and life changing journey. Thank you to my friend and mentor Mr. Jim Mann, for your interest in my work and for all of our coffee get togethers!

Finally I end by thanking and acknowledging my family: my dad Bud, my sisters Emi and Mary Jo and the bedrock of my life, my husband Elvis and kids Adam and Elly. Your support, love and encouragement has meant so much to me and without it I could never have reached this point.

## **Dedication**

For Elvis...

For believing in me, encouraging me, and for all the work you do supporting and caring  
for our family.

## Prelude

### Waiting for Home<sup>1</sup>

I can't even stand up properly  
If I wasn't here  
I'd be in a care home

Well, my health keeps going  
My wife says we won't prepare  
A celebration of life yet,  
You know?

But...I don't know...  
There's not much else I can do.  
Even if I was home now  
With this problem, what would I do?  
Be in a wheelchair?

I'd rather be at home

And so...I think..  
Actually a care home sounds good  
At a care home I might find  
Some people I can work with  
Or talk with...  
That'd be good

---

<sup>1</sup> Written with excerpts from Mr. Powell's interview

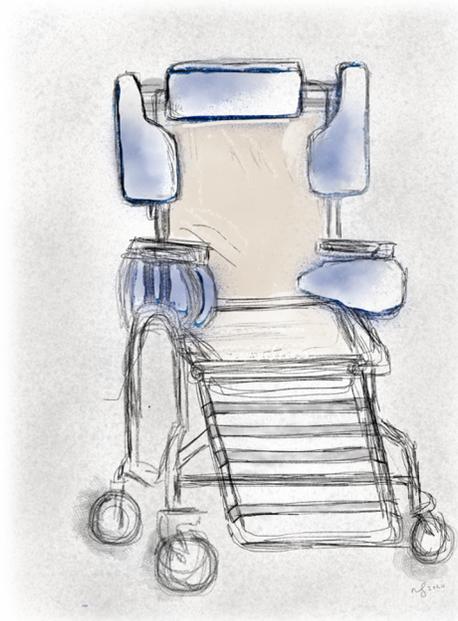
## **Chapter 1: Introduction**

### **1.1 Identifying a Research Problem**

I have been a registered nurse for over twenty years, much of that time working as a community health nurse, practicing in clinic settings and in people's homes. A few years ago, I started working on a casual basis as a transition nurse in a local hospital. While patients preparing to be discharged home fell under my purview of care as a transition nurse, it was Alternate Level of Care (ALC) patients who were not being sent home and thus, did not require my services, who consistently came to my attention. ALC patients were noticeably different than the type of patients that I had come to expect from a hospital unit. Most of the hospitalized patients I came into contact with were hooked up to intravenous lines, and were regularly receiving nursing and other health care interventions, such as wound care, physiotherapy, medical testing and lab work. The ALC patients that I encountered on the various hospital units no longer required the type of intensive medical and nursing care normally associated with a hospital stay. The majority were elderly, and I discovered that many of them were living with dementia and were waiting in hospital for a long-term care bed.

Apart from noticing that ALC patients did not seem to fit the image of a typical ward patient, it was apparent that caring for them, particularly those with a dementia diagnosis, was challenging for hospital staff. It was not uncommon for ALC patients living with dementia to be labeled as aggressive or behaviorally challenging. Furthermore, ward staff struggled to provide care for ALC patients, often because they were busy caring for other patients who were still acutely ill. I noticed that care for ALC patients living with dementia often involved placing them in their wheelchairs or Broda chairs (see Illustration 1) close to nursing stations where nurses and

other personnel could “keep an eye on them”. As a casual employee, I was routinely assigned to various units and as a result, realized that there were ALC patients on most of the different wards throughout the hospital. I also observed that ALC patients, particularly those living with dementia, could end up staying in hospital waiting for many weeks or even months for suitable discharge plans to be arranged.



**Illustration 1: Broda Chair**

As a community health nurse, I had not been previously aware of ALC patients. However, working as a transition nurse, I began to realize that ALC patients were fairly common in hospital settings. As a novice researcher about to begin doctoral studies, I wanted to know more about this specific patient population. I also started to question whether more could be done to better care for ALC patients, especially those living with dementia. Additional questions evolved, such as: what is acceptable in terms of older adult care in the hospital setting? Why are older people living with dementia waiting for such long periods in hospitals? As well as, what

does this mean for their wellbeing and overall health? I felt that there was something within this myriad of questions, observations and concerns that was worth looking into, but was not quite sure what that was going to look like, or if in fact this was a worthwhile avenue of inquiry. All of this eventually led to this research study, a situation where practice and inquiry have intersected. This then was the beginning, the practice-based context from which this study first took shape.

## **1.2 Background**

### **1.2.1 Dementia, older adults and the hospital setting**

Dementia is a global concern and increasingly much needed attention is being given to dementia issues worldwide (World Health Organization, 2017). Dementia is a progressive and degenerative condition that is characterized by its “gradual and unrelenting” (Sanders & Morano, 2008, p. 194) nature. Exact disease presentation can vary, but dementia is commonly associated with symptoms that include loss of memory, reasoning and judgment, as well as changes in mood and behaviour (Alzheimer Society Canada, n.d.). At this time, there is no cure for dementia and globally it is expected that up to 115 million people could be living with some form of the condition by the year 2050 (Alzheimer’s Disease International, 2009). From a Canadian perspective, there are over half a million people living with dementia in this country (Alzheimer Society Canada, 2017). In addition, dementia rates are on the rise, for although it is not a condition that is a normal part of ageing, dementia’s incidence increases as people age (Alzheimer Society Canada, 2017). This is of particular concern as there is now a greater proportion of older adults than younger people in most population groups (Statistics Canada, 2016), and overall, individuals are living longer than they used to (United Nations, 2015).

Thus, as people continue to age and live longer and more are diagnosed with dementia, these statistics have significant implications from a health care and nursing perspective,

particularly in the context of hospital care for older adults living with dementia. This is because it is increasingly common for hospitalized patients to not only be older, but to also have a dementia diagnosis (Sampson, Blanchard, Jones, Tookman & King, 2009; Singh, Varanasi & Williamson, 2014). Some studies report that up to 70% of hospital beds are utilized by people over the age of 60, with 25% of them diagnosed with a dementia or some form of acute confusion (Tadd et al., 2011).

Despite these numbers, there is ongoing concern that older patients living with dementia do not always receive optimal care while hospitalized (Cowdell, 2010a; Cowdell 2010b; Sampson et al., 2009; Tadd et al., 2011), in part because many health professionals feel unprepared and poorly trained to care for elderly patients, especially when there is a dementia involved (Clissett, Porock, Harwood & Gladman, 2013; Digby, Lee & Williams, 2017). Furthermore, hospitalization in older adults has been associated with significant physical deconditioning and functional decline that can occur rapidly and results in poor outcomes such as decreased autonomy and quality of life, as well as increased possibility of institutionalization (Graf, 2006; Guy, Laerman & Justo, 2012). These risks are exacerbated when combined with cognitive impairment (Graf, 2006). Certainly, hospital admissions for people living with dementia are associated with many negative outcomes, such as longer hospital stays and higher rates of mortality (Dewing & Dijk, 2014). Unsurprisingly, hospitalized older people living with dementia are at higher risk for institutionalization, and many of these patients end up designated ALC (Jutan, Langlois & Damiano, 2013).

### **1.2.2 Alternate level of care**

Patients who stay in hospital once their health has stabilized are designated ALC (McCloskey, Jarrett & Stewart, 2014). In other words, ALC patients are no longer acutely ill, but require an alternate level of care that cannot, for a variety of reasons, be provided at home.

This often occurs in patients with complex conditions, such as dementia, when overall care needs exceed what can be managed in the home setting (McCloskey, Jarrett, Stewart & Nicholson, 2014). Generally, ALC patients tend to be over the age of 80, are often female and are usually admitted to hospital following an emergency room visit (Lavergne, 2015).

The Canadian Institute for Health Information (CIHI, 2009) reports that ALC accounts for up to 14% of Canadian hospital days, a utilization of up to 7,500 acute care beds per year (Sutherland & Crump, 2013). In terms of British Columbia (the context of this research), there were over 460,000 hospital days that were designated ALC in 2018/2019 (Office of the Seniors Advocate, 2019). Many ALC patients, particularly those living with dementia, are waiting in hospital for long-term care beds to become available (CIHI, 2009). In addition, ALC patients living with dementia account for up to one quarter of all ALC hospitalizations, as well as over a third of total ALC days in hospital (CIHI, 2009). Overall, ALC patients living with dementia experience long waits for long-term care, sometimes waiting in hospital for several months, prolonging their time in the hospital system (Walker, 2011).

It is important to note that colloquially, ALC patients are often called “bed-blockers” (Meadus, 2014), referring to the fact that long-term use of acute care beds has detrimental effects on the flow and overall usage of a hospital, and effectively “block” beds from being used by other patients who actually require acute care-based services. As such, it is not surprising that much of the existing research examining ALC focuses on the impact these patients have on the acute care system in terms of bed utilization and the movement of patients throughout the hospital (McCloskey, Jarrett & Stewart, 2014). In recent years, several organizations across Canada have focused on ALC and have released research and policy documents stressing the growing issue that is ALC, portraying it as a pressing problem that needs to be addressed

(Fransoo et al., 2013; Lavergne, 2015; Ontario Hospital Association, 2012; Sutherland & Crump, 2013). In general, literature such as policy reports tend to focus on preventing hospitalizations in the first place so that patients do not end up being designated ALC and take up valuable space in hospital.

### **1.3 Distilling the Research Question**

Overall, there is little research that focuses specifically on the care experiences and needs of ALC patients living with dementia (Costa & Hirdes, 2010), and what it is like for them to wait for long periods of time in hospital (Wilson et al., 2014). This is concerning as ALC patients living with dementia are especially vulnerable, particularly as they end up staying the longest in hospital, a health care setting where older patients are known to have poor outcomes (Barnable, Welsh, Lundrigan & Davis, 2015). While there is definite worth in findings ways to prevent unnecessary hospitalizations that could result in ALC designations and long waits in hospital, it is also necessary to acknowledge that preventing ALC altogether is likely unrealistic, especially in light of our aging population and concomitant increases in dementia prevalence. Thus, there are valid concerns that more patients living with dementia will continue to be designated ALC in coming years. As a result, these patients' needs and experiences should be examined and considered as part of understanding and dealing with the problem of ALC in our hospital systems.

While ALC is often discussed in the literature as a systems issue that needs to be fixed, it is also a significant human issue, and the perspectives of those the system affects the most - ALC patients - are not well accounted for in the literature. The small amount of research that does exist reveals that ALC is a distressing and challenging experience for patients and their families

(Kuluski, Im & McGeown, 2017; Kydd, 2008; McCloskey et al., 2014). In addition, the perspectives of ALC patients living with dementia are not well represented in the literature. This is a significant gap. Research is needed that focuses on the human costs and effects of ALC designation and long-term hospitalization, emphasizing the care experiences and needs of these patients rather than the systems “blockage” they represent.

In distilling the various practice-based questions and concerns first identified at the beginning of this chapter, the main motivation of this study was to contribute to improving hospital care for ALC patients with living dementia. This then relates to the research question that drove this particular study: *What perspectives and experiences of ALC patients living with dementia could inform understandings of how to improve their care in hospital?* This research question was developed to address the fact that very little is known or understood about being designated ALC from the perspective of ALC patients living with dementia, while clearly demonstrating a commitment to recognizing their needs and improving care.

#### **1.4 Research Approach**

In order to answer the research question above, I used Interpretive Description (ID) as the research approach. ID is a qualitative method conceived by Canadian nurse researcher Dr. Sally Thorne and her nursing research colleagues in the late 1990s (Thorne, Reimer Kirkham & MacDonald-Eames, 1997). ID was developed in response to frustrations and discomfort regarding established social science methods of qualitative inquiry that did not exactly meet the discipline and practice-oriented research goals and perspectives of nurse researchers and nursing science (Thorne et al., 1997). As nursing research in the qualitative domain grew in the last part of the 20<sup>th</sup> century, nurse scholars were noticing that their work was often restricted by the

methodological rules of the social science methods most commonly being used (Thorne, Reimer Kirkham & O’Flynn-Magee, 2004). As such, ID “departed from the specific methods dominating qualitative nursing research at the time, and reflected the evolution of qualitative methodology within the disciplinary domain of nursing” (Thorne et al., 2004, p. 1).

Rather than an alternative method altogether, ID is more of a methodological orientation to qualitative research (Thorne, 2016). An important distinction of the ID research approach is that it is grounded in and oriented toward the development of disciplinary knowledge that will be useful in the practice setting (Thorne, 2016). In other words, ID is a qualitative approach that enables researchers “to find a way to do the kind of applied qualitative research that could generate the kinds of understandings of complex experiential clinical phenomena that would be optimally relevant and useful to the practice of nursing and other professional disciplines...” (Thorne, 2016, pp. 29-20). This approach was well suited to my dissertation research as the idea for this study first emerged in practice, and the main goal of this study, to improve the hospital care of ALC patients living with dementia, was similarly rooted in the practice setting. In the end, the ID study detailed in this dissertation involved gathering data from ALC patients living with dementia, family members, and nurses on hospital units over the course of several months. Overall, this included participant observations of patients and general observations in the care setting, as well as interviews and informal conversation.

## **1.5 Overview of the Dissertation**

In the first part of the dissertation, I provide important background and context for the research that took place. This includes an examination of pertinent literature in Chapter Two in regards to the phenomenon of ALC and hospitalizations for patients living with dementia.

Specific dementia literature has also been examined and presented to provide further context in terms of current health care practices and understandings. The first part of this dissertation also contains an in-depth discussion (Chapter Three) of ID as the chosen research approach, including an overview of the theoretical and disciplinary perspectives that scaffold this study. This section of the dissertation concludes with Chapter Four, which details the research methods that were used, as well as the analysis process that led to the study's findings. In the second half of this dissertation, the study findings are presented, beginning with Chapter Five where I provide important context for the findings. The main findings are presented over the course of Chapters Six through Eight. Chapter Nine includes a thorough discussion of the findings and implications for practice. This final chapter also focuses on study limitations and considerations for future research, bringing this dissertation to a close.

## **1.6 Chapter Summary**

This research study evolved from my nursing practice as a transition nurse, whereupon it became clear that there is a population of hospital patients whose health care needs could benefit from research. To date, there has been little research that examines the hospital experiences and care of ALC patients living with dementia, particularly from their perspective. Exploration of the experiences and perspectives of ALC patients living with dementia has proven to be an intricate and multi-layered undertaking, a process that is detailed in the chapters to come. Adequately recounting their experiences and perspectives in a manner that does justice to their deeply personal accounts while providing knowledge that will be useful in improving care has similarly been a complex process. I invite you into this process, as I begin to lay out the grounds for and foundations of this study, ultimately taking you into the experiences of ALC patients

living with dementia as they wait for home.

## **Chapter 2: Review of Pertinent Literature**

### **2.1 Overview**

ALC is a specific health system phenomenon, and while the discussion in Chapter One raised the issue of the human costs that this designation has for patients and their families, it is helpful to explore in depth how ALC is considered in current policy and health care literature.

Accordingly, the first section of this chapter explores what exactly an ALC designation is and what it means from a systems perspective. This chapter also discusses current policy trends that aim to address ALC concerns, and provides an overview of existing research that considers the perspectives and experiences of ALC patients. It is important to note that it has been challenging to find studies that take into account the perspectives of ALC patients living with dementia.

Thus, this chapter also focuses on issues related to dementia, examining social discourses and the experiences of older people living with the disease. Finally, this chapter considers how existing societal attitudes not only shape how ALC and dementia are approached as a “problem” in our health care system, but also determine in many ways how these subjects and experiences are researched overall.

### **2.2 Exploring the ALC Phenomenon**

#### **2.2.1 ALC as a designation**

It is beneficial at this point to reiterate the definition of ALC. As stated earlier, an ALC designation is given to patients who remain hospitalized, and are unable to be discharged despite being medically stable. This is because “for many of these hospitalized patients, the complex clinical and social post-acute care they need is not available, possibly ranging from family care

providers to residential care arrangements. In the interim, these patients wait in hospital beds for discharge into the community” (Sutherland, Liu, Repin & Crump, 2012, p. 1). In terms of the number of ALC patients consistently reported in Canada, 84% enter the hospital system following an unplanned and emergency admission, most are elderly and over the age of 80, and often there is a diagnosis of dementia (Turcotte, Daniel & Hirdes, 2020; Lavergne, 2015). Of all ALC patients, about 50% are waiting for long term care, while the rest are eventually discharged to assisted living facilities or return home with increased supports (Sutherland & Crump, 2013).

It is difficult to find up to date data reporting how long ALC patients stay in hospital in Canada. As per 2008-2009 data, 62% of Canadian ALC patients stayed in hospital over a week, while 24% stayed more than one month (CIHI, 2010). That same year, about 5 percent were designated ALC for over 100 days (CIHI, 2010). From a British Columbian perspective, 2013/2014 statistics reveal that there were 397,416 hospital admissions, accounting for over three million hospital days overall (Lavergne, 2015). Of these days, 12.6% or 398,756 days were designated as ALC (Lavergne, 2015). More recently, the Office of the Senior’s Advocate in British Columbia has released data that reveals that approximately 466,000 hospital days were designated as ALC in 2019.

Interestingly, rates of ALC use can vary substantially across different regions within provinces (Wait Time Alliance, 2015), and often rural areas will have longer lengths of stay compared to urban locales, likely due to there being fewer community resources in rural settings (Lavergne, 2015). Recent statistics (2018-2019) on the CIHI website *Your Health System* also report a wide variation of patient days in ALC across the country, from 13.2% in British Columbia to 19.7% in Newfoundland and Labrador. During the same period, Canadian territories accounted for 0.0% days in ALC in Nunavut, 9.3 % in the Northwest Territories, and 25.9% in

the Yukon. According to CIHI 2018-2019 statistics, ALC patient days are consistently highest in the Atlantic provinces, possibly due to an older population in this region (Canadian Medical Association, 2015). This is reflected in a 2014 study by McCloskey, Jarret, Stewart & Nicholson that examined ALC in two New Brunswick hospitals, reporting an average length of stay in hospital of 380 days. Regardless of differences in rates across the country, ALC is recognized Canada-wide as a significant health system issue (CIHI, 2011; Canadian Medical Association, 2015).

### **2.2.2 ALC as a health system issue**

ALC is a specific Canadian term used in the health literature of this country (Lavergne, 2015). However, it is a phenomenon similarly recognized in other parts of the world, often referred to as *delayed discharge* in the health services literature of countries such as the United Kingdom, Italy and Australia (Glasby, Littlechild & Pryce, 2006; Manzano-Santaella, 2010; Bo et al, 2016; Salonga-Reyes & Scott, 2017). ALC data collection and monitoring first began in Canadian hospitals in 1989 as part of an effort to differentiate between hospitalizations requiring acute versus non-acute care (CIHI, 2012). As part of this monitoring, ALC statistics are reported in CIHI's Discharge Abstract Database (DAD) (CIHI, 2012). The DAD collects and tracks information that pertains to hospital discharges, such as administrative, clinical and demographic data (CIHI, n.d.).

According to DAD guidelines, patients are designated ALC based on “a medical decision that the patient does not require further acute care services” (CIHI, 2009, p. 2). This decision is usually made by a physician and is documented in the patient's chart (CIHI, 2012). Following this decision, specific ALC paperwork is filled out, often by nurses, which eventually makes its way to hospital records where the information is entered into a computer database (Rankin &

Campbell, 2006). There are specific codes based on the International Classification of Diseases (ICD) called ICD-10-CA codes that Canadian hospitals use to record when patients are designated ALC that include specific ALC reason codes (CIHI, 2018; Fransoo et al., 2013). These ALC codes can differ slightly depending on factors such as discharge destination, for instance whether a patient is expected to move to a care home, or eventually return home. As such, the documentation of ALC designations requires extra work by hospital staff and might not always be completed accurately or in a timely fashion (Fransoo et al., 2013), which could account for concerns that ALC rates might be under-reported in Canada (Sutherland & Crump, 2011). There are also concerns regarding how consistently patients are identified as ALC, as well as whether they have been designated and coded as ALC as soon as they should be (CIHI, 2009).

### **2.2.3 ALC as a measure of performance**

While there may be concerns regarding the consistency and possible limitations of collected ALC data, what does exist “is sufficient to paint a picture of ALC across the country and contribute to discussions on appropriate care for ALC patients” (CIHI, 2009, p.2). A common aspect of ALC revolves around its characterization as a performance metric of how well a hospital is *efficiently* providing care (Pennery & Henry, 2008). Essentially, from a system’s point of view, an ALC designation represents inefficiency (Pennery & Henry, 2008; Sutherland & Crump, 2011). As stated by Sutherland & Crump (2013), “ALC represents an inefficient use of hospital resources - these patients are occupying beds, staff time and equipment that could otherwise be used by patients waiting in the emergency department or those who have had their surgeries postponed” (p. 27). Thus, discussions of ALC often revolve around the detrimental downstream effect ALC patients have on hospital systems as a whole (Lavergne, 2015), and

policy documents aimed at addressing ALC in Canada tend to focus on preventing its designation in the first place.

### **2.2.3.1 Proposed policy solutions**

As the majority of ALC patients end up in hospital following an unplanned and emergency room admission (84%), proposed solutions often revolve around proactively preventing emergency visits and hospitalizations from occurring (Lavergne, 2015). For instance, there has been an increased focus on primary care reforms aimed at providing comprehensive and preventative health care to community patients at risk for ALC (Lavergne, 2015). Part of this involves what has been called care integration. This is similar to British Columbia's Integrated Primary and Community Care Initiative, where efforts are made to better connect hospitals, home and community care, primary care, and mental health services in preventative care planning and delivery processes (Cohen, 2012). The goal of care integration is to better connect what has traditionally been silos of care in order to prevent fragmentation of services, to make care more efficient, and to prevent or reduce ALC utilization (Sutherland & Crump, 2011). Care integration has been found to be effective in the United States (US), but these models of care are challenging to compare to what is happening in Canada, as the American health system is quite different (Lavergne, 2015). For instance, US Medicare patients who cannot be discharged home from hospital are usually sent to Skilled Nursing Facilities (SNFs) for further treatment and care, rather than remain in the acute care setting (Britton et al., 2017).

A possible remedy to decrease ALC lengths of stay often discussed in Canadian health literature is to increase both acute and post-acute care capacity - in other words, to provide more hospital and long-term care beds. Some consider this an expensive and temporary solution which could lead to possibly more ALC patients taking up available spaces in hospital, leading to

further capacity issues in long term care (Sutherland & Crump, 2013). In addition, a research study that analyzed long term care bed supply in Canada found that provinces that had a higher bed supply per capita did not necessarily experience fewer ALC hospital days (Sivananthan, Doupe & McGregor, 2015), while a study conducted in the UK found that there was only a modest response to availability of care home beds for delayed discharges in hospitals (Gaughan, Gravelle & Siciliani, 2015). Other strategies such as Home First policies involve offering increased supports for ALC patients at home to avoid waiting for facility placement in the hospital setting whenever possible (Lavergne, 2015; Starr-Hemburrow, Parks & Bisailon, 2011). Waiting at home in one's own environment is usually preferable for patients and thought to be beneficial for many reasons. It not only frees up hospital beds, but also decreases risks of hospital-acquired infections. Often it also allows patients to wait for their preferred care home rather than the first available bed (Starr-Hemburrow, Parks & Bisailon, 2011). The Home First approach has resulted in a reduction of ALC patient days in Ontario (Starr-Hemburrow et al., 2011), and this policy has also been implemented in BC, although its impact on ALC use is still to be determined (Lavergne, 2015). This option assumes that, in addition to increased supports provided by the system, the home situation is amenable to the patient's needs, and this would include adequate family support and a safe and accessible living environment. For patients without appropriate supports available or suitable living arrangements, waiting at home could be problematic. In addition, waiting at home can increase pressure on caregivers, who are already at high risk for caregiver burnout (Nguyen, 2009).

Along with primary care reforms and Home First strategies, some provinces such as British Columbia and Ontario have also been incorporating financial incentives referred to as activity-based funding (ABF), where hospitals and programs are paid specific monetary sums based on

the type and amount of activities that are performed (Cohen, 2012). The goal of ABF is to reduce costs and increase efficiency (Sutherland, McGrail, Law, Barer & Crump, 2011), and can include financial incentives for such activities as discharges from hospital (Sutherland & Crump, 2013). Incentivizing discharges puts pressure on hospital staff to move patients out of acute care beds as soon as possible, and could account for some inappropriate discharges (Lavergne, 2015). ABF likely adds another dimension to the notion of ALC patients as system “blockers”, for if patients cannot be discharged, particularly long-term ALC patients, then hospitals are effectively blocked from receiving a financial incentive.

Regardless of different approaches to preventing or dealing with ALC, it seems that overall “there are few documented policy examples that have successfully reduced ALC use” (Lavergne, 2015, p. 20). This is significant as ALC rates are projected to rise in coming years as our population of older adults continues to age (CIHI, 2012). This is also a concern when considering the effect that an ALC designation has on the quality of care that patients receive, as will be discussed in the following section.

#### **2.2.4 ALC as a patient experience**

It is important to note that once patients have been coded as ALC, they are charged a daily fee for staying in hospital, often referred to as a co-payment (Kuluski et al., 2017). This co-payment or per diem fee is similar to what patients would pay once in a subsidized long-term care home (Fransoo et al., 2013). ALC patients usually require minimal nursing care, and while this reflects fewer acute care needs, they also often do not have access to the same level of services that they could expect at most long-term care homes, such as regular social activities and rehabilitative care (McCloskey et al., 2014). As such, the fairness of being charged a co-payment for being hospitalized while receiving few specialized services is a concern for many

ALC patients and their families (Kuluski et al., 2017).

While ALC is associated with specific financial costs for patients, it can also become a *diagnosis* that defines patients, and their continued reason for hospitalization. For instance, when nurses begin to use ALC as a diagnosis, rather than actual nursing or medical diagnoses, concepts and values that are distinctly managerial and systems-oriented start to permeate clinical practice and can affect care. As Rankin & Campbell (2006) explain,

We observed nurses referring to patients through this lens (appropriate vs inappropriate, important vs less important needs, deserving vs undeserving candidates for care, or ‘bed blockers’). The cost-relevant framework enters into how nurses make their own decisions about who gets their time and attention, and who doesn’t. The circle is closed (p. 86).

As mentioned previously, while there is much literature that examines the effect that ALC patients have on the health care system, there are few studies that directly explore and take into account the experiences of patients in terms of what it is like for them to be designated ALC. This is a significant gap in ALC knowledge, especially as the designation seems to not only classify these patients a certain way, but can also characterize their care experiences.

Studies that do explore patients’ perspectives reveal that receiving an ALC designation and waiting in hospital for long periods of time is a challenging experience for patients and their loved ones. For instance, Cressman and colleagues (2013) conducted a narrative study of elderly ALC patients and their caregivers in Ontario, and found that feelings of ongoing uncertainty characterized their hospitalization experience. McCloskey et al. (2014) interviewed ALC patients and family members in New Brunswick and discovered that the participants were acutely aware that they were using a hospital bed when they were no longer sick. The participants were also aware that they were not a priority when it came to patient care (McCloskey et al., 2014).

Similarly, a 2008 ethnographic study in the UK demonstrated that older patients designated as *delayed discharges* felt quite anxious about the future, and felt they were not always well supported by hospital staff (Kydd, 2008). An Albertan study, utilizing mixed methods, examined the impact of waiting in hospital for facility care (Wilson et al., 2014). Qualitative findings involved themes of loneliness and isolation as part of the waiting process, and demonstrated that the hospital is a bleak place for ALC patients to wait in (Wilson et al., 2014). A 2019 scoping review of the literature focused on patient and caregiver experiences with delayed discharges found that uncertainty characterizes the patients' time in hospital, and that they can experience mental and physical deterioration (Everall et al., 2019). In addition, a recent qualitative study by Kuluski et al. (2020) revealed that ALC is a confusing term that does not resonate with patients and family members, that communication from the care team is poor, and that patients tend to experience functional decline. Overall, research that addresses the perspectives and care experiences of ALC patients demonstrates that long-term hospitalization is an ordeal, and significantly, that patients and family members notice that the care they receive is different than non-ALC patients.

### **2.2.5 ALC and the dementia experience**

One limitation that these existing studies share is that while they endeavoured to represent the perspectives of ALC patients and their families, the ALC experiences of patients living with dementia were not explored. As has been previously mentioned, up to one quarter of all ALC hospitalizations in Canada are associated with some form of dementia (CIHI, 2009). In addition, ALC patients living with dementia often end up with the longest hospitalizations, usually because they are waiting for a care home bed. This was evident in a recent retrospective population-based study (Aaltonen, El Adam, Martin-Matthews, Sakamoto & McGrail, 2020)

conducted with administrative data in BC, which demonstrated that dementia was not only the strongest predictor of ALC designation, but that dementia and waiting for long-term care accounted for a higher number of ALC days.

Thus, this lack of the perspectives of ALC patients living with dementia in the literature is significant and of concern. Kuluski et al.'s (2017) exploratory qualitative descriptive study in Ontario attempted to address this discrepancy, although by interviewing carers of patients diagnosed with cognitive decline and not by directly involving the patients themselves. Their study describes ALC hospitalization as an uncertain and confusing experience where the quality of care received by patients living with dementia was not always consistent (Kuluski et al. 2017).

As it is challenging to find literature that directly examines the experience of ALC patients living with dementia, it is helpful to look at existing research examining the acute care setting and the care of non-ALC patients living with dementia to provide much needed context. There is growing research activity in this field and a recent integrative review of the literature from 2005-2015 by Digby et al. (2017) is particularly illuminating in this regard. An important finding in this review is that research shows that hospitalized patients living with dementia can feel patronized, acutely stigmatized, as well as subjected to derogatory remarks. In terms of a nursing perspective, Digby et al. report that care for this population of patients is often considered as unskilled, non-prestigious and mundane work. The authors point out that the tendency of placing lower value on nursing people living with dementia is a reflection of societal values and attitudes, in that these individuals are often valued as less of a person. This has been reflected in other scholarly work where the person living with dementia can be seen as a “demented other” (Naue & Kroll, 2009), with the unfortunate effect of negatively stereotyping and marginalizing the person (Sabat, Johnson, Swarbick & Keady, 2011). As Dewing & Dijk (2014) explain, it

seems that there is “a lack of valuing people with dementia, or a (perhaps inadvertent) culture of devaluing of individuals with dementia in acute hospital settings, thereby disregarding their needs, personhood and emotional well-being” (p. 111).

According to CIHI (2011), “by definition, appropriate care is about providing the right care, to the right person, in the right setting, at the right time” (p. 42). There seems to be a consensus in extant literature that ALC patients, especially those living with dementia, are not the right patients for the hospital setting. This is not surprising considering that most research that examines older adult health outcomes when hospitalized show that a hospitalization has negative long-term effects on overall health and wellbeing (Touhy, Jett, Boscart & McCleary, 2012). Research has also shown that this is exacerbated in elderly patients who also have a diagnosis of dementia (Dewing & Dijk, 2014). Thus, it makes sense that ALC patients are not well suited to the hospital environment. However, the use of terminology such as *right* evokes the word’s natural opposite, that of *wrong*.

The fact that so much of the literature is either focused on the detrimental effects that these patients have on the health care system, or on how to prevent ALC from occurring in the first place, is concerning. It can to a certain extent place these patients in the wrong, even though it is not ALC patients’ fault that they are faced with waiting in hospital for a more suitable care option. Existing literature also ignores how to provide the *right kind of care* for ALC patients, particularly those living with dementia who tend to stay the longest in hospital. ALC designations will continue to occur in our hospitals, especially as the Canadian population of older adults ages and grows. Thus, one cannot help but wonder why there is so little research that examines the issue of ALC in our hospital system from the perspective of the patients’ experiences? This is challenging to answer, and requires examining how older people with living

dementia are considered and valued within society.

## **2.3 Examining Dementia and Prevalent Social Discourses**

Existing social discourses and understandings revolving around dementia and the aged likely have a lot to do with why the perspectives of older adults living with dementia are often neglected in research. Certainly, the challenges of involving people living with dementia in research, particularly those with advanced disease, play a factor in this, and these issues and concerns are discussed later in this dissertation. Nevertheless, it is worth first considering and discussing how society tends to view people living with dementia. As part of this, it is important to consider how aging and dementia are interconnected.

### **2.3.1 Dementia and aging**

While not every person diagnosed with dementia will be an older adult, aging and dementia are closely linked, particularly within our social consciousness. Along this line of thinking, it is helpful to examine social constructions of aging, as there are powerful and commonly held societal attitudes and assumptions that influence the aging experience (Powell & Hendricks, 2009), and by extension of this, the dementia experience as well. For instance, there is a propensity within society to homogenize older adults (Innes, 2009; Beard, 2017), as a result of which they can be regarded as a uniform group of “non-contributors to society” (Gee, 2002, p. 752). In addition, aging is often viewed as problematic, despite it being a natural process in the life course (Johnson, 2005). This problematization of aging is apparent in society’s fixation with *healthy aging* or *aging well* discourses, where aging becomes a problem when it does not align within these frames of reference (Katz & Calasanti, 2015). The tendency to problematize and homogenize later life is also apparent with dementia, where societal views of the disease tend to

be quite negative, revolving around a discourse of fear, deficit and tragedy (Birt, Poland, Csipke & Charlesworth, 2017; Mitchell, Dupuis & Kontos, 2013; Innes & Manthorpe, 2012). This is evident in media descriptions of the “dementia crisis” (Adey, 2015; Vanderklippe, 2016), as well as in policy reports such as *Rising Tide* (Alzheimer Society, 2010), all portraying dire societal consequences as the population ages and more people are diagnosed with dementia. As Mitchell et al. (2013) explain:

These images, coupled as they usually are with the tragedy discourse of being doomed, gutted, ravaged, taken over by a beast, and turned into the living dead, perpetuate a deep and pernicious fear of, and disregard for, persons with dementia. (p. 2)

According to McParland, Kelly & Innes (2017), dementia as a complex life experience tends to be reduced to a dichotomous discourse of either *tragedy* or *living well*. The *tragedy* discourse, as alluded to above, is related to the bio-medicalization of dementia whereby the illness and the experience of living with it is focused on loss of function and decline (McParland et al., 2017). McParland et al. explain that the opposite of this point of view is the *living well* discourse, “where the emphasis has shifted from loss and decline to supporting remaining strengths and recognizing enduring personhood” (p. 259). The *living well* point of view has had many positive influences on perceptions of dementia, as well as on policies of care, but one of the limitations of this particular perspective is that it can exclude and marginalize those living with more advanced dementia. According to McParland et al. (2017) this causes a tendency for society to create different systems of care and rules for those who are deemed to have aged unsuccessfully and as they state, “in the context of the successful aging paradigm, those with dementia who are most frail have failed the living well test” (p. 262). This particular perspective is intriguing when considering the hospital care of ALC patients living with dementia, for as

figurative *bed blockers*, they can be seen as the unsuccessful aged, stuck in a system of care that values them less than other patient populations.

### **2.3.2 The bio-medicalization of dementia**

The previous paragraph referred to the bio-medicalization of dementia, which in many ways limits understandings of the dementia experience. Overall, dementia tends to be constructed as a biomedical concern, largely because of its classification as a neurological condition and a disease of the brain (Bartlett & O'Connor, 2010). Furthermore, within this medical discourse, focus tends to be on the losses, symptoms, and changes associated with the disease and how it can be treated medically (Bartlett & O'Connor, 2010). While there is nothing wrong with a biomedical focus in and of itself, it can be concerning when the experience of dementia is examined or considered solely from this vantage point. A common criticism of the biomedical viewpoint is that it is reductionist in nature, reducing illness to its symptoms and the people experiencing disease to body parts and specific diagnoses (Innes, 2009; Philpin, 2008).

The biomedical construction of illness does not really allow for people to think about post-illness lives in different ways apart from what the disease means for the body (Frank, 2004). As Frank states, the ill body “is often alienated, literally ‘made strange’” (p. 305). This point of view is significant when one considers what it must be like to be diagnosed with dementia. Dementia is often viewed as an illness that creates a changed person or a stranger who has been altered by the many losses incurred by the disease over time, particularly losses and changes to memory. As it has been stated when describing dementia’s effects, “patients are a shadow of their former selves – profoundly disoriented, incoherent, amnesic, and incontinent” (Kaiser & Panegyres, 2007, p. 398). This is quite a hopeless description of the disease’s deterioration process, and one that likely stems from a leading theme in dementia discourse, that of loss and

suffering.

### **2.3.3 Dementia and the health care context**

It is not surprising that people living with dementia may be subjected to different systems of care and rules as McParland et al. (2017) suggest, especially when considering the strength of the biomedical model and dementia's ties to age-related discourses. Certainly, when it comes to systems of care, this is evident in health care, and particularly in hospitals. Unfortunately, there is a tendency in health care to infantilize, intimidate, stigmatize and objectify people living with dementia (Mitchell et al., 2013). This can be attributed to the dominant paradigm in society and in health care, where dementia is seen as a disease that is "tragic" and to be feared, which in turn propagates disregard for those living with the disease (Mitchell et al., 2013). Nevertheless, it is important to confront this dominant discourse, and part of this involves critically examining the language that is commonly used to describe and talk to people living with dementia. As Mitchell et al. (2017) state, "the language we use, over time, gradually becomes institutionalized into accepted patterns of discourse, which shape our activities and practices (i.e., how we act) and our social relationships and organization (e.g., how we relate)" (p. 3). This certainly has interesting connotations when reflecting back to this chapter's earlier discussion on ALC designation, particularly in terms of how a patient is designated and coded as ALC in tracking systems, as well as informally "coded" as a particular kind of person and patient on hospital wards. The terminology associated with ALC is in many ways quite stigmatizing, clearly designating these patients as requiring an "alternate" type of care.

### **2.3.4 The social imaginary of dementia**

Overall, the prevalent social understandings and views of dementia can be encapsulated into what some have called the social imaginary of dementia (Birt et al., 2017). As philosopher

Charles Taylor (2002) explains, “the social imaginary is that common understanding that makes possible common practices and a widely shared sense of legitimacy” (p. 106). The social imaginary of dementia can affect how people living with the disease are treated and tends to be “embedded within the end-stage of the disease where an individual may be seen as frail and dependent, almost wholly unable to participate within their social world: socially dead” (Birt et al, 2017, p. 204). Birt et al. further attribute such a powerful discourse of decline to sociological understandings of the fourth age. The fourth age, in and of itself another form of social imaginary, occurs when older adults no longer seem to be aging “well” or “getting by”, and similar to the social imaginary of dementia, is associated with loss of social status (Gilleard & Higgs, 2010). These socially constructed discourses of decline and decay are important to consider, not only because of the negative effect that they have on older people living with dementia, but also because of the way they can influence policy and care practices (Innes & Manthorpe, 2012).

An excerpt from a 2013 dementia policy report by the Champlain Dementia Network in Eastern Ontario has been included below. This excerpt was taken from the beginning of the report where dementia as a public health priority is discussed.

Dementia is the leading cause of dependency and disability among older persons. Poor understanding of the condition creates barriers to timely diagnosis, which can in turn lead to large gaps in treatment, care and support and a subsequent cascade to dependency. This in turn takes its toll of the resilience of the family unit and increases the likelihood of high costs associated with increased dependence and morbidity. The total economic burden of dementia in Canada has been projected to grow from \$15B in 2008 to \$153B by 2038. (Champlain Dementia Network, 2013, p. 8)

While this paragraph makes important points about the need for timely diagnosis and the unfortunate gaps in treatment and support that exist for people living with dementia, it is also easy to pick up on the discourse of decline that Birt et al. (2017) are referring to above, in terms of dementia and the “cascade to dependency”. The focus on the economic burden of caring for people with living dementia is likewise not hard to miss in this statement. We live in a society that regularly institutionalizes older citizens in long-term care settings, and where waiting for long periods of time in the hospital setting for facility “placement” is the norm. As such, it is important to challenge the current system of care, as well as predominant discourses of decline and tragedy. We must re-orient the focus towards improving quality of life and wellbeing for people living with dementia, rather than on the costs and dire social repercussions of an aging and dependent population.

## **2.4 Chapter Summary**

While this study has critically examined existing care practices and inquired into how care can be improved for ALC patients living with dementia, part of justifying why this was necessary requires looking into what is already known about ALC and dementia care. It has been important to take the time to explore and consider existing literature, in the form of research and policy documents, regarding ALC in Canada’s health care system. This chapter has discussed what ALC designation means from a patient and systems perspective. This chapter has also examined the social discourses that play a significant role in shaping the experiences of older people living with dementia, as well as those who are designated ALC in our hospital systems. Although there is a strong focus on ALC in extant literature, particularly when it comes to policy documents, much of the emphasis is on how ALC patients detrimentally affect hospital

functioning and the efficacy of the system. There is little attention given to the patient experience, especially for those living with dementia. It is within this gap in the literature and existing research that this study was focused, and the following chapters detail the steps that were taken to bring to the fore the perspectives and experiences of the patients themselves.

## Interlude I

### Sharing Moments<sup>2</sup>

She speaks expressively with me  
Using her hands to gesture  
At times laughing and smiling  
Sometimes opening her eyes wide

She smiles and nods  
When people come and talk to her  
But then gives me a “knowing look”  
When they leave  
As if she doesn’t think  
They are that great

Suddenly she makes a face,  
As if she is imitating someone  
She doesn’t like  
And we both burst into laughter  
At the same time  
It’s a nice shared moment...

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<sup>2</sup> Written with excerpts from Field Notes for Mrs. Ho 10.31.2019-01.09.2020

## **Chapter 3: Scaffolding the Study**

### **3.1 Overview**

The following chapter lays out the methodological, theoretical and disciplinary underpinnings of this Interpretive Description (ID) study. This includes an in-depth overview of ID as a research approach, as well as exploration of the theoretical and disciplinary perspectives that ground this work. Throughout this project I drew on two theoretical perspectives that have influenced dementia care and research, specifically the lenses of personhood and social citizenship. In addition, I was guided by core nursing values and understandings, in particular the interpersonal and relational nature of nursing care. I “scaffolded” this study within these theoretical and disciplinary understandings, providing an important foundation from which to guide my approach and interactions with the study’s participants. Furthermore, the perspectives I lay out in this chapter guided the design of the project, in terms of how I gathered and analyzed data, and influenced how I considered the impact of this work in relation to dementia care and nursing practice.

### **3.2 Methodological Considerations**

According to Thorne (2016), ID is a research approach that is well suited to the types of research questions that require an interpretive lens, as well as an “inductively derived description of a phenomenon” (p. 53). In addition, as part of being a methodological orientation rather than a methodology in and of itself, ID “shamelessly encourages borrowing from the full universe of available design techniques as appropriate to the nature of the research question at hand” (Thorne, 2016, p. 39). This flexibility allows for a variety of design configurations and strategies

free from the paradigms and rule structures normally associated with traditional methodologies (Stephens, 2018). From a disciplinary perspective, ID was developed to facilitate the creation of knowledge that could be of direct use to nursing and other applied disciplines (Thorne, 2016). This is an important distinction, particularly as this positions ID researchers to work towards knowledge that can be of practical use within a disciplinary field, rather than facilitating the production of knowledge that is simply theoretically interesting (Thorne, Stephens & Truant, 2016). As such, it is the discipline's epistemological standpoint that provides the logic around which an ID study is designed (Thorne, 2016).

### **3.2.1 Nursing knowledge**

At this point, it might be helpful to unpack some of the main ideas that tend to revolve around discussion of nursing epistemology. The debate around what comprises nursing knowledge and which conceptualizations should take precedence is ongoing (Rycroft-Malone, Seers, Titchen, Harvey, Kitson & McCormack, 2004; Thorne & Sawatsky, 2014). Nevertheless, most in nursing agree that its disciplinary knowledge is diverse and made up of many forms of knowledge (Carper, 2009; Tarlier, 2005). This makes sense from a disciplinary and nursing perspective, when one considers the complexity within practice, where a practitioner must be able to rely and draw on diverse forms of knowledge and ways of understanding the world, in order to address complex nursing problems. In addition, nursing knowledge as an entity is commonly understood as existing to holistically improve and support health and wellbeing (Sakamoto, 2018). In fact, nursing has “a social mandate to contribute to the good of society through knowledge-based practice” (McCurry, Revell & Roy, 2009, p. 43). Thus, an ID study that is rooted in nursing epistemology is driven by an overwhelming purpose to derive useful knowledge from the inquiry process. In this sense, the decisions that a researcher makes, ranging

from methods to analysis, are undertaken with the goal of developing knowledge that will inform practice in some way, and will make a difference for those that nurses care for.

### **3.2.2 Underpinnings of ID studies**

In addition to its commitment to developing disciplinary knowledge, there are certain “foundational underpinnings” (Thorne, 2016, p. 82) and common assumptions that are expected to gird ID studies. These are clearly laid out in Sally Thorne’s (2016) book *Interpretive Description: Qualitative Research for Applied Practice* and include acknowledging that ID studies occur in a naturalistic context as possible, and are attentive to subjective and experiential knowledge, as well as to time and context. In the case of this study, this involved a focus on the context of the acute care setting for patients designated ALC, as well as the greater social context of being an older person living with dementia. In terms of being attentive to time, this meant focusing on the period of time that patients were designated ALC.

This study was also sensitive to important subjective and experiential factors, namely that while it is becoming more common in dementia research to take into account the person’s subjective point of view and experience, dementia is still on the most part a socially constructed experience and understood as a disease where the person is “robbed” of their sense of self (MacRae, 2010). As such, it was vital to look beyond common and negative assumptions of the dementia experience, and undertake to explore the experience of ALC patients living with dementia from their perspectives as much as possible

Another of ID’s assumptions involves recognizing that human experience is socially constructed, and that there are multiple constructed realities, rather than simply one, of any given phenomenon (Thorne, 2016). Understanding that there are multiple realities, ID researchers “recognize that theory that will help us to understand a practice phenomenon must emerge from

or be grounded in that phenomenon” (Thorne, 2016, p. 82). This was an important aspect to account for in this study, for as with any complex life experience, there were likely many factors and influences that affected the ALC patients’ experiences. Thus, as I wanted to better understand the care experiences of ALC patient living with dementia, in order to improve hospital care, I needed to approach the ALC experience in a way that allowed for the multiple realities of ALC patients to emerge. This meant being grounded in the phenomenon of the everyday care and hospital experiences of ALC patients living with dementia, and being open to the different ways that this occurred and was experienced.

### **3.3 Theoretical Grounding**

While ID studies are not framed or informed by a specific theoretical or conceptual framework (Thorne, 2016), it is important to clarify that nursing work is not an atheoretical undertaking. Nor is nursing research. Nurses and nurse researchers bring distinct theoretical lenses to patient, client and study participant interactions, to each act of nursing, and to the process of discovery that is inherent in research. Thus, this section focuses on two particular perspectives and approaches to dementia care and research that have guided me throughout this study. Specifically, I discuss the personhood and social citizenship lenses from which to consider dementia care, discourse and research. These ways of thinking about dementia have provided important ways to consider the dementia experience in care settings and research contexts, particularly from the person living with dementia’s perspective.

#### **3.3.1 Personhood and dementia**

Tom Kitwood’s work (1997) on personhood is seminal in the field of dementia, in that it challenged prevailing biomedical views that tended to focus exclusively on dementia as a disease

of the brain and how it affects cognition. Kitwood was concerned with how people living with dementia could be de-personalized. He wanted to contest common conceptions of dementia as a “living death” and worked towards improving person-centered care. As part of his person-centered approach, he argued that a diagnosis of dementia does not in itself diminish personhood; rather this occurs as a result of how people living with dementia are treated by others. His much often cited definition of personhood is as follows: “It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p. 8). This was quite a revolutionary view at the time, that other people could have a role in granting personhood to another person.

Kitwood (1997) also established the term *malignant social psychology* to describe the effect of depersonalizing a person living with dementia, and the detrimental effect this can have on that person’s sense of who they are. His work and emphasis on personhood has been called a social-psychological theory of dementia care, and continues to be significant today as it provides an alternative to traditional points of view that focus on dementia as a disease of decline and deficiency (Kaufmann & Engel, 2016; Innes & Manthorpe, 2012). The earlier discussion of the stigma and marginalization that people living with dementia face is an important reminder of the effect a biomedical standpoint can have in terms of reducing people to the confines of their disease, particularly in the context of this work where patients are powerfully defined by their ALC designation and dementia diagnosis. This highlights the need for theories that present alternate points of view, particularly those that are person-centered.

While Tom Kitwood’s work has been very important in the field of dementia care and research, there has been some criticism of his perspectives. Unfortunately, Kitwood passed away quite suddenly in the late nineties before he was able to further develop his work. As a result,

some have felt that his ideas of personhood are unfinished and unrefined, and possibly not radical enough (Dewing, 2008). According to Jan Dewing (2008), a nurse and well-known dementia scholar, Kitwood's work has been criticized for the way that it places "power of persons without dementia over those with dementia" (p. 9). This is a valid perspective, especially when considering the language that Kitwood uses in his definition of personhood as quoted above, particularly in his use of the word "bestow".

The act of bestowing something upon another person, in this case the bestowing of personhood, does seem to negate any agency or control for the person living with dementia. Rather, it seems that some people have complete control in conferring personhood on others. It also promulgates stereotypes of incapacity and lack of status, of being dependent on others for all things, which is a common problem for people living with dementia. Furthermore, in connecting other scholarly discussions with this line of critique, another shortcoming with Kitwood's individualized focus is that it does not take into account the wider socio-cultural factors that could lead to problems such as marginalization and loss of personhood (Innes & Manthorpe, 2012). However, while there may be limitations to Kitwood's personhood perspective, his work is significant because he was able to show that personhood is not defined in terms of cognitive capacity (Dewing, 2008). As such, it should not be rejected altogether.

In fact, the personhood perspective figured prominently in my early scholarly work. As a Master's student, my thesis focused on the personhood of younger people living with early onset dementia and helped me to consider new ways of considering the dementia experience. Reading Kitwood's and other scholars' (eg: Hughes, 2001; Caddell & Clare, 2011; Sabat et al., 2011) work on personhood in dementia care and research also influenced my nursing practice and research interests. It broadened my understanding as to what it means to provide person-centered

care as a nurse. More importantly, the personhood lens has laid the groundwork for other perspectives and ways of thinking about dementia care and research that have a wider lens, specifically that of social citizenship.

### **3.3.2 Social citizenship and dementia**

For people living with dementia, social citizenship has been defined “as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible” (Bartlett & O’Connor, 2010, p. 37). Overall, social citizenship is envisioned as a fundamental right that should be accorded to people living with dementia, regardless of stage of illness. Other important aspects of this perspective is that it is concerned with:

...revealing and exploring the myriad of ways in which people with dementia are maintaining and asserting personhood, forming coalitions, claiming rights becoming politically active, exercising agency, taking control, risks and responsibilities, speaking up for themselves and others, and dealing with the demands of citizenship within the context of having dementia (Bartlett & O’Connor, 2010, p. 5).

It is common for people living with dementia to experience changes and losses to social status once diagnosed with the illness (Bartlett, 2014), or to be “positioned as passive actors” (Brannelly, 2011, p. 663). Thus, research and care practices that recognize the social citizenship of people living with dementia have been important in countering and challenging common and negative social discourse regarding dementia (Birt et al., 2017; O’Connor & Nedlund, 2016). Furthermore, there is a growing body of research utilizing a social citizenship lens, helping to expand discussions on how society can not only better meet the needs of people living with dementia, but also shift prevalent and negative attitudes and views about what it means to live

with this condition (O'Connor & Nedlund, 2016; Dupuis, Kontos, Mitchell, Jonas-Simpson & Gray, 2016; Phinney, Kelson, Baumbusch, O'Connor & Purves, 2016). The social citizenship lens has been described as a framework that “posits a rights-based – as opposed to needs-based – lens...” (Wiersma et al., 2016, p. 416), recognizing and valuing the possibilities for growth and active participation in life for those living with dementia, rather than simply or solely focusing on their losses and care needs.

As Bartlett & O'Connor (2007) state, “discussions about citizenship are by implication discussions about power, and in particular, the lack of power afforded to some citizens in relation to others” (Bartlett & O'Connor, 2007, p. 111). In terms of the ALC and dementia context, power structures abound in a hospital setting from the powerful biomedical agenda to patient hierarchies, whereby ALC patients living with dementia are seen as less prestigious patients to care for. In addition, when it comes to dementia care, “an implicitly hierarchical power structure is assumed – physicians have the most power, health and social care professionals hold power over the family and the person with dementia and family members hold power over the person with dementia” (Bartlett & O'Connor, 2010, p. 80). With these existing structures in mind, it has been important to consider the power that comes implicitly in my role as a researcher and as a nurse working within this hierarchy and as someone who has a lot of sway and influence within the health care setting. These considerations lay an important foundation for discussing the disciplinary perspectives I brought to this research project.

### **3.4 Disciplinary Grounding**

I view nursing as the act of “moving between the universal and the uniquely particular with people as they live their health experiences, in order to collaboratively reveal possibilities in

human healing” (Spenceley, 2004, p. 205). With this perspective in mind, I have always tried to relate to each person I come into contact with in my role as a nurse, as a person in his or her own right, realizing that I share in the human experience simply by being another human being. At the same time, I realize that while we all may relate to one another in terms of life’s universal themes (health, illness, death, etc...), each person’s life is ultimately a unique phenomenon and thus, we all experience and understand life and health in our own ways. Overall, I have found that something special happens at the intersection of caring for and being with other people when the act of nursing is approached in a way that acknowledges both the universal and the particular. This involves being able to connect relationally with others at the most human level, trying to see the other person in all of their own uniqueness, recognizing where one’s own being possibly overlaps with others’ in terms of experiences and perspectives, as well as where one’s particular and unique self is situated.

### **3.4.1 Relational practice**

From a nursing point of view, relational practice can be defined as a “humanely involved process of respectful, compassionate and authentically interested inquiry into another (and one’s own) experiences” (Hartrick Doane, 2002, p. 401). Hartrick Doane & Varcoe (2013) go further in discussing and promoting a relational lens of inquiry for nursing practice, a reflexive process that takes into account contextual factors and how they are integrally connected to one another and shape each “ person’s identity, experience, interpretations, and ways of being in the world” (p. 150). Overall, when considering these discussions of relational practice, it is clear that not only an interaction between people is occurring, but that there is a process of inquiry, of being interested in another human being, as well as a back and forth movement of understanding and acknowledgment taking place. I believe that this dialectic can be key to meeting another person

in a figurative space that allows for recognizing, appreciating and promoting the key aspects of nursing that are meaningful to me, and certainly figured prominently in this work, especially when I was trying to determine assent during data collection. This is a process I discuss in more detail in the following chapter.

### **3.4.2 Navigating the relational space**

In order to further unpack these ideas of working within a relational space, particularly in how I situated myself relationally in this study, it has been helpful to draw upon theologian and philosopher Martin Buber's (1958/1986) seminal work *I and Thou*. Buber was interested in two forms of relationships in terms of how humans engage with the world and with one another, specifically *I-Thou* and *I-It* relationships (Friedman, 2001; Kitwood, 1997). An *I-It* relationship takes place between a subject and object, where one person is only relating to another "indirectly and nonmutually" (Friedman, 2001, p. 25). On the other hand, an *I-Thou* relationship is reciprocal and mutual (Friedman, 2001). Interestingly, Buber did not see the *I* as existing solely on its own, separate from *It* or *Thou*. As he explained, "there is no I taken in itself, but only the I of the primary word I-Thou and the I of the primary word I-It" (1958/1986, p. 20). This implies that for the *I* to exist, it has to be in some form of relationship, whether with an *It* or a *Thou*. In addition, one can move back and forth between *I-Thou* and *I-It* states of being when interacting with others, but it is only in the *I-Thou* relationship where the self and the other are both fully recognized as truly human. As Buber (1958/1986) states, "the primary word *I-Thou* can only be spoken with the whole being" (p. 19). Similarly Tom Kitwood (1997) stated, "to be a person is to be addressed as Thou" (p. 10).

This idea of a relational *I-It* or *I-Thou* certainly is relevant within both nursing and research contexts. Endeavouring to authentically and compassionately be involved and interested in

another's experiences evokes a sense of the *I-Thou* relationship. In addition, the co-existence and movement between the *I-Thou* and *I-It*, as envisioned by Buber, also makes sense from a nursing and research perspective. In regards to nursing, the discipline has long upheld its commitment to holistic practice, of caring for the whole person. Nevertheless, in practice, it is often necessary and important to focus on a specific aspect of the patient, for instance the part of a person's body that is ill or injured. This could be interpreted as an *I-It* interaction, and certainly there are aspects of nursing that are very task-focused. However, it is possible within a nursing interaction with a patient for there to be movement between the two relational states. This could occur as part of focusing on a specific task that once completed would allow a nurse practicing relationally to enlarge his or her focus, acknowledging the patient as a whole person and recognizing that there is more to them than the body part that requires treating.

Similarly, from a research perspective, it would be possible to move back and forth between the *I-It* and *I-Thou* states when interacting with research participants. It is also possible that a researcher could function only from an *I-It* perspective to the detriment of building a relationship, as well as to the research process. For instance, a researcher could become so focused on working through an interview guide, making sure that all the questions are asked, and possibly miss out on an opportunity to dig a little deeper on a particular subject, if not attentive enough in the interaction to pick up a significant vocal inflection or statement made by the participant. It is also quite possible for a researcher to become so fixated on the end result, on "discovering something", that the participant becomes a means to an end, and not a relational being that is part of the discovery process.

As part of a relational process of discovery, and influenced by personhood and social citizenship perspectives, I endeavoured to approach the participants as partners and resources in

the discovery process. To clarify, this meant that this was not only *my* research project, with my interests and motivations to complete a PhD dissertation driving the process. This was a research project that strove to put patients living with dementia who have been designated ALC at the forefront. This was about their subjective experiences. As part of relationally navigating interactions with others, as well as acknowledging the possibilities of moving back and forth between *I-It* and *I-Thou* relationships, I tried my utmost to establish the *I-Thou* whenever possible.

Within the context of dementia research, the significance of an *I-Thou* relationship has further import, particularly when considering the tendency for people living with dementia to be seen as a “demented other” (Naue & Kroll, 2009) or as a “subaltern” (Gilmour & Brannelly, 2010). Kitwood (1997) was effectively describing negative *I-It* relationships when he coined the term *malignant social psychology*, when describing the effect that depersonalizing and objectifying a person living with dementia can have on their sense of personhood. As Puurveen (2016) states, “maligning care practices (e.g., stigmatization, invalidation, and objectification) and assumptions that the disease of dementia erodes all capacity, agency, and thus selfhood do very little to value the person” (p. 52). Similarly, it could be stated that maligning research practices, whether intentional or not, such as objectifying the participant, certainly does not value the person. Overall, situating oneself within a relational space that acknowledges the importance of seeing the whole person while allowing for movement between relational states when needed, facilitates the recognition that the other is an active social being, a person with his or her own inherent worth and value. This relational positioning was vital in my research encounters with patient participants, and guided me throughout the project.

### **3.4.3 Further considerations**

I realize that as a PhD student and researcher, I have had the privilege of being able to exercise a considerable amount of influence and power. For instance, I can communicate easily, both verbally and in writing, am familiar with the hospital setting and have the knowledge and expertise to navigate its complexity. This is in stark contrast to ALC patients living with dementia, who are likely much older than me, may not be able to communicate with ease, have been labeled ALC, and who tend to be viewed as patients who should not be occupying space in acute care. Earlier I discussed how I have felt uncomfortable with what I have witnessed and been a part of in practice in terms of the care of ALC patients in hospital. These experiences in practice formed the genesis of this project, and must be acknowledged, especially since what I witnessed in the acute care setting and in my role as a nurse caused me to question what I was seeing and, in many ways, wonder if more could be done for ALC patients living with dementia. All of these considerations have meant that throughout the research process, I had to think carefully about how I was working and interacting with the study's participants. I tried to be mindful of my actions and interact with participants in a way that recognized personhood, agency and active citizenship, rather than reinforcing existing power structures. In the following chapters, I provide detailed accounts of how I oriented and conducted myself in order to meet patient participants in a respectful and empowering space, and also explore these considerations further in the Reflexivity section (Chapter Four).

### **3.5 Chapter Summary**

This chapter has provided an overview of ID as a research approach. The discussion in this chapter has also focused on the theoretical and disciplinary scaffolding that I built around

this study to provide solid grounding from which I was able to explore the experiences of ALC patients living with dementia with confidence, sensitivity and purpose. In accordance with the complex realities of disciplinary practice, ID research work is an intricate process of conducting qualitative research that is attentive to “context, situation and intent” (Thorne, 2016, p. 30). Similar in some ways to Kincheloe’s (2005) description of “Bricolage” research, where the process of inquiry “exists out of respect for the complexity of the real world” (p. 324), an ID study is similarly complex, but is built around its goal to add to disciplinary knowledge. In addition, each ID study is uniquely informed by the context in which the research is situated, as well as by the particular theoretical and disciplinary perspectives the researcher brings to the process of inquiry. It is with the theoretical and disciplinary understandings discussed in this chapter and that were brought to the discovery process, that I undertook the data collection and analysis phases of this research study, which brings us to the following chapter.

## Chapter 4: Methods

### 4.1 Overview

This chapter describes the research process that took place, focusing on the specific sampling, recruitment and data collection methods that were utilized in this ID study. In addition, I discuss how the consent process was approached, specifically for the patient participants who took part in this study. Detail is similarly provided in regards to assent and dissent processes that were used throughout the data collection phase. I also discuss the processes I engaged in as part of analyzing, interpreting, synthesizing and presenting the data, and conclude this chapter with a discussion on rigour.

### 4.2 Study Setting

This study took place at a large community hospital in a city in the Greater Vancouver Regional District of British Columbia. There are several reasons why I chose this site. While there is a large tertiary hospital close by, it reports lower rates of ALC than the chosen study site, possibly because many long-term patients are repatriated back to community hospitals once their health has stabilized. Thus, I expected that at the community hospital study site there would be a sufficient number of ALC patients living with dementia from which to recruit.

In addition, I was familiar with this particular hospital setting, as I have worked as a transition nurse in all five of its patient wards. I anticipated that being familiar with many of the staff and leaders at the hospital might facilitate entrée and access as a researcher. These expectations were not unfounded. In fact, I was pleasantly surprised at how quickly I was able to recruit a suitable number of patient participants, as well as family member and nurse participants.

The hospital leaders were amenable to my presence as a researcher and helped to facilitate access to the hospital units. In the end, I engaged in observations on three separate hospital units at the study site: a general medical unit, an Acute Care for Elders (ACE) unit, and a Stroke/Sub-Acute unit.

#### **4.2.1 Description of the hospital units**

The general medical unit I spent time on routinely serves patients of varying ages and medical needs, and there are not any specific admission criteria for this unit. Patients who experience a stroke and who require lengthy rehabilitation are most often admitted to the Stroke/Sub-Acute unit, but this ward can also admit patients with general medical concerns. Admission to the ACE unit is reserved for patients over the age of 75 with complex medical concerns, with emphasis on geriatric care and maintaining independent function. The ACE unit was undergoing renovations during the time I spent on the unit, which meant that sections of the unit were closed off for construction, and several patients who were considered ACE patients were currently admitted on other hospital units.

The staffing complement of the three different units are similar and include Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and Care Aides, who provide the majority of the patients' hands on care. There is a Patient Care Coordinator (PCC) on each unit, a leadership position held by an RN, who is responsible for the day-to-day operations of the ward. Each unit has a designated Transition Nurse (TN) and Clinical Nurse Educator (CNE), as well as Allied health care professionals such as Physiotherapists (PTs), Occupational Therapists (OTs) and Social Workers. Hospitalists (Physicians) and specialized medical teams, such as the Geri Psych team, attend to the patients' medical needs. The physical set up on the three units is similar in that each has a nursing station, usually in the middle of the ward. Hallways, along which the

patient rooms are situated, loop around the nursing units. Most patient rooms serve two to four patients. The ACE unit is the only locked ward where visitors have to be buzzed in and out.

### **4.3 Reviewing the Research Question**

The research question guiding this study was: *What perspectives and experiences of ALC patients living with dementia could inform understandings of how to improve their care in hospital?* From the way that this question is phrased, it is obvious that an important source of information was meant to come from ALC patients who live with dementia. Prior to starting recruitment and data collection, I anticipated that it might be difficult at times to gain access to the patients' subjective experiences given that most ALC patients living with dementia contend with fairly advanced disease. In addition, there could be other sources of important information and insight about the ALC experience, such as family members and health care staff, that could help to contextualize what ALC patients living with dementia are experiencing. While I was committed to approaching the study from a patient-oriented and person-centered lens, I was also aware that the ALC care experience for those living with dementia would be complex and multi-faceted. Thus, it made sense to engage with family members and health care providers, along with the ALC patients themselves.

### **4.4 Sampling and Recruitment**

#### **4.4.1 Sample**

The total sample size for this study was 21 participants. This included patient participants (n=8), family member participants (n=6) and nurse participants (n=7). All participants were identified using purposeful sampling. Purposive sampling is useful when participants with

understanding or experience of the phenomenon of interest are being purposefully sought out (Creswell, 2013; Robinson, 2013). As such, specific inclusion criteria were utilized:

#### **4.4.1.1 Patient participants - Inclusion criteria**

1. Individuals living with dementia, or with cognitive challenges/confusion
2. Individuals designated ALC
3. Individuals who had a primary caregiver or contact person able to take part in the consent process as necessary.

#### **4.4.1.2 Family member/caregiver participants - Inclusion criteria**

1. Individuals who were family members or designated caregivers of an ALC patient living with dementia
2. Individuals who spoke and understood English

#### **4.4.1.3 Nurse participants - Inclusion criteria**

1. Nurses working at the study site who were regularly involved in the direct care or care planning of ALC patients living with dementia.
2. Individuals who spoke and understood English

#### **4.4.2 Patient participant recruitment and sample**

Recruitment for this study began in an unexpected fashion. Following a meeting with the manager and director for Patient Flow and Transition, where paperwork for operational approval was signed, a meeting was arranged where I was able to meet with the director of acute care services, patient care coordinators and transition nurses. I was able to explain the purpose of my study and research plans at this meeting. To my surprise, recruitment and data collection started that same day when I was invited to come to one of the hospital units by a PCC after the

meeting. I began general observations, and recruited the first patient participant that same afternoon.

Originally, my recruitment plan involved posting recruitment posters in the different units and common areas in the hospital, with the intent to inform potential patient, family and nurse participants about the study, inviting them to contact me if they were interested in participating. I did not end up needing to use recruitment posters, as the PCCs were very helpful in identifying potential participants and introducing me to patients and family members. The local health authority's research institute also posted study information and recruitment information on their website, which is accessible to the general public. I was contacted by a member of the public who was interested in meeting with me to discuss her family member's experiences in hospital. I had an interesting and illuminating conversation with this person, but was not able to recruit her family member, despite his dementia diagnosis, as he did not meet the inclusion criteria for this study.

I had expected that the PCCs would facilitate entrée to the units, and would be helpful in identifying potential participants. However, I did not think that recruitment would occur as quickly as it did, nor solely through the PCCs. In most cases, recruitment of patient participants occurred after talking with PCCs, where they identified patients who were ALC and who also had a dementia diagnosis, and whom they felt would be amenable to my approaching them and their family members about participating in the study. After these conversations with PCCs, I would approach the patient, usually when their family member was present, would introduce myself and explain my research project. I would provide them with study information letters (See Appendix A) and I was always careful to explain that participating in the study was completely voluntary and would not affect their care and discharge planning. I phoned two

family members to make first contact, as it was difficult to be on the unit at the same time they were. Following brief phone calls where I introduced myself, I emailed study information letters to these family members, and met them at the hospital at a later date once they indicated an interest in having their family member participate in the study.

In the end, I recruited one patient participant from the general medicine unit, one from the ACE unit and six patient participants from the Stroke/Sub-Acute unit. While there were ALC patients living with dementia on all three units, there were more patients who met the study's inclusion criteria on the Stroke/Sub-Acute unit during the time that I was present at the hospital collecting data. From what I gathered talking to staff on the wards, there often are more ALC patients on this particular unit. There were likely other factors that influenced my recruitment efforts, such as the ACE unit was undergoing renovations during my data collection phase, which made it harder to connect with the PCC who was very busy re-organizing the unit.

As mentioned, I recruited eight patient participants for this study. As I began to spend time with patient participants and collect data, I noticed that I was amassing copious field notes that were rich and dense in nature. I halted recruitment of patient participants after recruiting eight participants as I felt that the data that I was accruing was more than adequate to answer the research question. This was a decision that I discussed with my supervisor and committee members, and we reached a consensus on when to stop recruiting new patient participants. The eight patient participants present as a sample of varied individuals, with a wide range of ages, personal characteristics and background. The participants ranged in age from 69 to 94 years of age and included four men and four women.

This sample also included a husband and wife couple who were hospitalized concurrently. All the patient participants were admitted to the hospital via the emergency room

and reasons for admission included falls associated with traumatic brain injury, stroke, recent heart attack and changes in mobility related to unresolved pain. Two of the patient participants had originally been in another hospital and had been repatriated to the hospital site where this research took place. Time spent as admitted patients in hospital ranged from approximately four weeks to nine months, and time spent as an ALC patient ranged from two weeks to seven months. Table 1 describes demographic and select descriptive characteristics of this sample.

**Table 1: Patient Sample Characteristics**

Patient Sample (8)	n
<b>Gender</b>	
Female	4
Male	4
<b>Ethnicity</b>	
Caucasian	3
Asian	5
<b>Age</b>	
60-70	1
71-80	1
81-90	4
91-100	2
<b>Hospital Unit</b>	
ACE	1
General Medicine	1
Stroke/Sub-Acute	6
<b>Length of Total Hospitalization (days)<sup>1</sup></b>	
0-50	2
51-100	3
101-150	2
151-200	0
201-250	0
251-300	1
<b>Time Spent as ALC Patient (days)<sup>2</sup></b>	
0-50	3
51-100	3
101-150	0

	151-200	0
	201-250	1
	Unspecified	1
<b>Discharge Destination</b>		
	Care Facility	6
	Home with Enhanced Supports	2

<sup>1</sup> Includes days spent as ALC/Range of Hospitalized days 21-268 days

<sup>2</sup> Range of ALC days 14-215 days

All of the patients except for one had a dementia diagnosis. The one patient who did not have an official dementia diagnosis was included in this study because this individual presented with confusion. Of the eight patient participants, one of them was never officially designated as an ALC patient. Despite not ever being designated ALC, this individual was considered “like an ALC patient”, as it was explained to me by staff on the ward. She was also designated “No Home First”, which was a classification that the study site utilized for patients who were deemed unable to return home, and was usually a precursor to ALC designation. As such, I felt that this individual met the criteria to participate in this study.

#### **4.4.3 Family member participant recruitment and sample**

I also recruited six family member participants, with the goal of further contextualizing and adding to the patients’ experiences. When I recruited patients, I also asked family members if they would be interested in participating in the study. Five of the family member participants were direct relations of patient participants, and were recruited at the same time that the patients were recruited. One family member participant did not currently have a relative in hospital, but was aware of my study. This participant was also a nurse employed at the hospital site and was aware of my study, expressing interest in participating in the study. This person had a family member living with dementia who had been an ALC patient about 18 months previously at a hospital in a different health authority. As such, this individual shared her family member’s

experiences as an ALC patient, and much of her account resonated with what the other family members discussed in their interviews, while also providing an interesting glimpse into the ALC experience at other hospital sites. All of the family member participants were provided with study information letters as part of the recruitment process (See Appendix B). Table 2 describes the demographic characteristics of the family member sample.

**Table 2: Family Member Sample Characteristics**

Family Member Sample (n=6)	n
<b>Gender</b>	
Female	2
Male	4
<b>Relationship to ALC Patient</b>	
Spouse	2
Child	4
<b>Age Range (years)</b>	
40-50	1
51-60	1
61-70	2
71-80	1
81-90	1

#### 4.4.4 Nurse participant recruitment and sample

Similar to the family member participants, I also recruited nurses to provide further context and perspective to the patient participants' experiences. While I was on the different units, I left study information letters (See Appendix C) with the PCCs regarding recruitment of nurses for the study. I also approached nurses in various positions who were involved in the care of ALC patients living with dementia, such as frontline nurses, transition nurses, educators, and nurse leaders in order to gain access to a variety of nursing perspectives. I stopped recruiting

nurses for the study once I had a varied sample. Overall, seven nurses participated in the study and Table 3 lists this sample's demographic information.

**Table 3: Nurse Participant Sample Characteristics**

Nurse Sample (n=7)		n
<b>Job Category</b>		
	Licensed Practical Nurses	2
	Registered Nurses <sup>1</sup>	5
<b>Gender</b>		
	Female	6
	Male	1
<b>Age Range (years)</b>		
	40-50	2
	51-60	5
<b>Job Tenure (years)</b>		
	10-20	2
	21-30	4
	31-40	1
<b>Education Level</b>		
	College Diploma	4
	Bachelor's Degree	1
	Master's Degree	2

<sup>1</sup> This included various positions: Unit nurse, Transition nurse, PCC, Clinical Educator, Nurse Leader

#### 4.5 Data Collection

As described earlier, ID researchers are encouraged to take advantage of the full range of existing qualitative research methods (Thorne, 2016; Thorne et al, 2016). Despite this inherent flexibility, it is vital to remember that ID studies are grounded in the research question that is guiding the study, and the drive to develop knowledge that will be useful to the practice setting (Kortje, 2016). Thus, there is an inherent logic in how methods are chosen in ID work, in that not all methods are necessarily useful or appropriate. The methods utilized in this study were chosen because they helped meet the goals of answering the research question and developing disciplinary knowledge as it relates to understanding and improving the care experiences of ALC

patients. They included a combination of participant observation with patients and general observations on the units, as well observations during patient rounds and meetings. This amounted to 106 total hours of observations. Other data collection methods included 14 semi-structured one-on-one interviews and several informal conversations.

Most of the data collection occurred over a four-month period from October 2019 to February 2020. I had an interview with a nurse scheduled in mid-March at the study site, which had to be cancelled due to the COVID-19 pandemic. I was able to re-schedule this interview in June, once pandemic restrictions started to ease. The period from October to February was an intense and very busy time, as recruitment of participants occurred quickly and subsequent data collection ensued rapidly as well. At several points in the data collection phase, I had several patient participants involved in the study at the same time. This meant that I spent long days at the hospital site, spending time with the participants at different points in their days. Between observation periods, I was able to fit in interviews with nurses and family members. While it was not ideal to be collecting data at such a pace, it was important to follow up with interested participants whenever possible, as discharges, especially to care homes, could happen quickly and unexpectedly. I never knew when patient participants and family member participants might be moving on from the study site. Similarly, nurses who were interested in participating often wanted to be interviewed on days they were working, usually during their breaks or at the end of their shifts, and I had to be prepared to respond to their availability and willingness to spend time with me.

Fortunately, there were periods of time during the data collection phase when patient participants had been discharged and I was actively recruiting new participants. During these times I was able to review my field notes and listen to audio recordings of interviews. This

allowed me time to consider the data I had already accrued and opportunity to be thoughtful and strategic about continued data collection. For instance, I began to realize that I had a lot of data, particularly observational data, that revolved around busy times of the day, such as in the early mornings and evenings when patients received a lot of hands on care. In response to this, I began to concentrate my observations during points of the day when there was not a lot going on for patient participants, to see and understand what was happening for them during these less busy times.

#### **4.5.1 Data collection with patient participants**

Conducting a study from the perspective of patients living with dementia presents particular challenges, especially as most are living with fairly advanced disease. I suspected that I would not be able to interview all of the participants in depth, which was indeed the case. Thus, participant observations were the main mode of data collection, and these were focused on the patients' care and daily hospital routines.

##### **4.5.1.1 Participant observations**

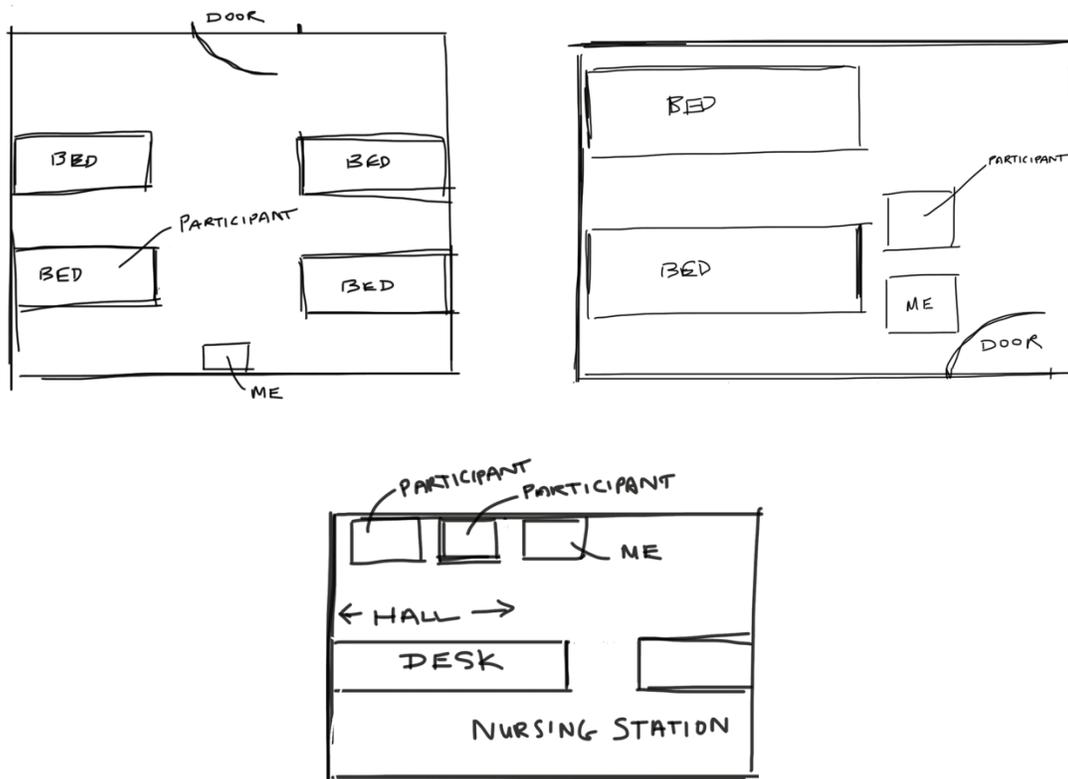
Participant observation as a research method is useful in highlighting the dynamic nature of relationships and behaviours in health care settings, as well as illuminating the experiences and perspectives of patients and the people they interact with within these settings (Booth, 2015; Mulhall, 2003; Watts, 2011). Of the 106 total hours of observations, I spent 100 hours with the patient participants. This occurred over 85 separate observations sessions. The sessions ranged in length from 15 minutes to just over two hours, and also took place at different points in the day. Observations that only lasted 15 minutes include sessions that were cut short when participants had to leave the ward for a scheduled test or procedure, or when a family member came to visit and wanted to take the participant for an outing to the cafeteria or to the coffee shop. I tried not

to spend more than two hours at a time with patient participants. Overall, my goal was to spend at least 12 hours with each participant, spaced throughout different times of the day in order to account for a full 12 hour nursing shift. I was able to follow all of the patient participants from the time of recruitment up to the day of their discharge, either home or to a care home. For some patient participants, this meant that I was not able to spend the planned 12 hours with them, as they were discharged before this goal was reached. However, I was also able to spend more than 12 hours with other patients, if they were not discharged in the immediate period after I had recruited them. By the time data collection concluded, hours of total observations for patients ranged from 8 to 16 hours.

I was also able to space out my time spent with the patient participants between the hours of 0700 to 2100, during different days of the week. By doing this I was able to account for how patients experienced their days in hospital from the beginning of the day shift when morning care occurred to the end of the day, when evening care was provided. This also meant that I was able to observe what was going on for patients and on the units at all the times throughout the day. Overall, I observed what was happening for patients as care was occurring, focusing on the patient participants' reactions and expressions (verbal and non-verbal) during these periods of time. I also took into account what was happening for patients when direct hands on care was not occurring. I focused on interactions with health care staff and family members, as well as with the other people they came into contact with over the course of their days. Many of these hours were spent with the participants in their rooms, usually by their bedside. Sometimes family members were present, and at other times they were alone.

I also spent time with participants when they sat in the hallways or by nursing stations, when they were in music therapy class, and for those that were able to ambulate on their own,

walking with them in the halls. On most occasions, I purposely sat next to patients and engaged with them whenever possible, as part of the person-centered focus and social citizenship orientation of the research. Along this line of thinking, I often refer to the observation sessions with the patient participants as “spending time with” or “visiting” with them. However, there were times when I observed patient participants from afar, although this usually occurred when patients were sitting in the hallways or by nursing stations when it seemed more appropriate to sit away from them.



**Illustration 2: Sitting with Participants (Sketches from Fieldnotes)**

Some of the reasons for sitting apart from participants and observing from a distance were that there sometimes was not enough room for me to join them where they were sitting, and at other times there was a lot going on in and around the patient(s) and I could better take in what

was happening from a further vantage point. By observing from afar, I was also able to take into account what it was like for patients to sit at a nursing station or in the hallway, when no immediate interactions were occurring. Whenever I observed from afar, I always would go up to them first to greet them and determine assent, and later come by to say goodbye when I was leaving

Throughout the observation sessions, I wrote field notes in a notebook that I carried with me at all times. I routinely recorded not only what I was observing, but also what I was hearing, sensing and sometimes smelling. The writing of field notes can be a complex process, affected by the environment that the researcher is working within (Condell, 2008). Due to the nature of observational work, it is not always possible to write field notes in the moment (Atkinson, 2015). For instance, there were times when I was not able to write field notes as I was concurrently observing, and in those cases I would find a quiet spot immediately afterwards in order to write down what I observed. This would often happen if a lot of activity was occurring at once, or if someone was talking with me and it did not seem appropriate to be writing extensive notes at the same time. When this would happen, I would often write “jottings” in my journal in the moment, using short descriptive notes to jog my memory later when I would be writing the full field note (Emerson, Fretz & Shaw, 1995). Over the course of all of the observation sessions, I amassed copious field notes, which I later transcribed into my computer. I have included a selection of field notes (See Appendix D) organized in a fashion that illustrates the span of times I spent with participants over the course of my observations, from early morning to the evening.

Emerson and colleagues (1995) recommend that researchers are transparent about what they are doing when writing field notes, and why they are taking notes when conducting observations. As they state, “openness avoids the risks and likely sense of betrayal that might follow from

discovery of what the researcher has actually been up to” (p. 21). While one might presume that a person living with advanced dementia would not realize that a researcher is jotting down notes, or remember any explanation that is provided, these types of assumptions serve to further stigmatize people, as well as negate any sense of active citizenship. Emerson et al. (1995) also point out that researchers in the field must depend upon well-developed interactional skills in order to determine whether it is appropriate to be openly taking notes. Certainly, approaching interactions in ways that promoted a relational space was critical throughout the time that I was collecting observational data. For instance, I often would show my notebook and pen to the patient participants whenever I sat down by their side and say things such as “Is it OK to take notes?” or “I’m going to write in my book, is that OK?” Most of the time, participants would nod to indicate that it was okay. A few times, I saw a participant frown or seem uncomfortable, and in those cases I would put my notebook in my bag, and later wrote detailed notes to the best of my ability as soon as possible following the observation period.

#### **4.5.1.1.1 Special considerations**

I did not exceed two hours of direct observation periods involving close interactions with participants, so as to minimize any potential negative impact on the participants, as well as on daily hospital care and routines. It was not my intention to make the hospitalization experience any more difficult for the participants, or get in the way of care being provided. Furthermore, guided by a social citizenship perspective, I did not want to reinforce stereotypes of passivity or use observations in a way that could depersonalize participants. I tried to keep at the forefront of all of my actions the understanding that each participant was an active social agent, and person in his or her own right. As such, whenever I could I tried to engage with the participants in conversation, meeting them in the space they currently occupied. In some cases this meant that I

sat and listened when participants wanted to talk about what they were feeling and experiencing in the moment. At other times, this meant that I sat quietly with participants, if they did not seem talkative or inclined to engage directly with me. I also used eye contact and gentle touch when it seemed appropriate, picking up on cues from the participants themselves, and from observing how family members and others interacted with each person. I was also very careful to make sure that my presence did not upset or bother participants, and if it seemed that my presence was unwanted, I always stopped my observations and conversations with participants immediately. I discuss these special considerations further and in more detail in the Assent section below.

#### **4.5.1.2 Interviews**

My goal was to engage in as many one-on-one semi-structured interviews with patient participants as possible to ask them directly about their care experiences. I had prepared an interview guide in advance (See Appendix E). Ultimately, I was able to engage in an interview with only one of the patient participants, which was audiotaped and later transcribed verbatim by a professional transcriptionist. Of the eight patient participants, three were able to converse with me in English. For the other participants, English was a second language and they either had lost their ability to speak English or had limited understanding to start with. One of the participants for whom English was a second language was also non-verbal. Of the three participants who could converse with me in English, one struggled with word finding, and the other had a significant and chronic delirium overlying his dementia, which meant that our conversations could veer off in surprising directions. The participant with delirium at times could experience distrust and suspicion of those around him, and I felt that he would not be comfortable with participating in an audio-taped interview. For the participant with challenges with word finding, I

did not want to cause undue pressure for her to engage in speech, especially if I was audiotaping her. For these participants, I engaged in informal conversations.

#### **4.5.1.3 Informal conversations**

The informal conversation I engaged in with participants occurred in the moment when they seemed open to and able to talk with me about their experiences as patients. These conversations were similar to go-along interviews where the participant and researcher engage in discussion while moving through the participant's social environment (Castrodale, 2018; Kusenbach, 2003). As the majority of the patient participants were unable to walk around on their own, I was not always able to engage in interviews "walking about" with them as the go-along method was originally conceived. However, in the spirit of the go-along interview, I was able to obtain "responses from participants while they actively inhabit[ed] specific contexts" (Carpiano, 2009, p. 264). This meant that I took my cues from the participants, and when they seemed open to talking with me, engaged in conversation with them in whatever location they happened to be in, whether lying in bed in their rooms, or seated in their chairs by the bedside or in the hallways.

I recorded what we talked about and what patients said in my field notes, explaining to the patients that I was taking notes during our conversations and receiving their verbal consent to do so. I had several informal conversations with the two patient participants who spoke English, but could not participate in an audio-tapped interview, over the course of the different times we spent together. For the patient participants who could not converse easily or at all in English, I would like to mention that we still engaged in conversation together. I would always speak to all of the patient participants, regardless of their ability to speak and converse in English. I would greet them each time I saw them, asking them if I could sit with them and how they were doing.

In fact, I often engaged in lengthy conversations with participants, where we each spoke our own languages and did not fully understand what each was saying to the other, but I feel that we were able to communicate with one another, and sometimes make ourselves understood. This was an important aspect of our interactions, and helped to ensure that our encounters together were person-centered in a way that facilitated a respectful and comfortable *I-Thou* space for them.

#### **4.5.1.4 Ethical considerations**

People living with dementia are most often thought of as being inherently vulnerable, due to the cognitive effects of the disease and how it can affect judgment and decision-making. As such, there are certain risks and challenges in involving people living with dementia in a research project, especially those living with advanced disease (Alexander, 2010). However, from a social citizenship perspective, it is important to involve people living with dementia in the research process as part of acknowledging their potential as active and socio-politically powerful citizens (Bartlett & O'Connor, 2010). Furthermore, those who may be considered most vulnerable still have a right to be heard (Wilson & Neville, 2009), and to not be excluded from any benefits that might come out of participating in research (Alexander, 2010). Finally, it is important to critically consider what it means to look upon another person and think them vulnerable. Do we confer unwanted vulnerability and frailty on others in our efforts to be protective? Thus, it is incumbent on researchers to overcome the challenges of involving “vulnerable” populations in research, particularly so that participants and others living similar life experiences can benefit from the potential knowledge and improvements in practice that may come out of the discovery process (Alexander, 2010).

#### **4.5.1.5 Consent processes**

Certainly, a main challenge in involving people living with dementia in research is ensuring

that proper consent is given to participate. According to the 2018 Tri-Council policy statement for ethical conduct involving humans, consent must be freely given, informed and ongoing. Participants must also fully understand the possible risk and potential benefits of participating, before consenting to take part (Pesonen, Remes & Isola, 2011). This is not always possible for people living with dementia, especially those living with significant symptoms and memory loss. Nonetheless, lack of capacity or incompetence in one area does not automatically predicate lack of competence altogether (National Council on Ethics in Human Research, 1996). Thus, it was important that I not assume that a person living with dementia should be unable to consent to participate. In fact, it is not only excluding, but also reinforces stereotypes of incapacity to immediately assume that a person is incompetent to consent simply on the basis of a dementia diagnosis (DuBois et al., 2012; Heggstad, Nortvedt & Slettebo, 2013; Sherrat, Soteriou & Evans, 2007). As such, I was prepared for receiving either consent from the patients themselves, or from their Representative/Temporary Decision Maker (See Appendix F & G)

In the end, only one of the patient participants was able to sign his own consent form. For the other seven participants, I had to ask family members to sign the consent forms on their behalf. While seeking this type of consent fulfills certain legal duties and ethical obligations, proxy consent does not align well with the view of persons living with dementia as active social agents. It also does not seem person-centered, and as Dewing (2002) succinctly states, “Quite simply, another person has made decisions on behalf of the person with dementia” (p. 160). The decision to ask family members to provide third party consent was reached in part by discussing patients’ capacity to consent with the PCCs, who had a good understanding of the patients’ abilities. For all the participants, I went to introduce myself and meet with them initially, prior to asking for consent from their family members. It was here that I often relied on my nursing

experience, for when I would first introduce myself to prospective participants, I could observe how they interacted with me and consider their level of comprehension in the moment. In many instances, it would be quite clear that I could not ask the person to sign a consent form on their own behalf. If this was the case, I strove to find other ways to engage the participants in the consent process. It was important to pay close attention to their body language when I was spending time with them, as part of taking into account whether they were willing to participate (Wilkinson & Novak, 2017). In other words, I endeavoured to move beyond getting a proxy consent form signed by a family member and be simply satisfied with that. Rather, I sought ongoing assent from participants, and was similarly always on the look-out for signs of dissent (Slaughter, Cole, Jennings & Reimer, 2007).

#### **4.5.1.6 Assent process**

As part of obtaining ethics approval from my university, I needed to provide an Assent Form for patient participants who could not provide their own informed consent. This was duly drafted, submitted to and approved by the Behavioural Research Ethics Board (See Appendix H). However, when it came to the practical use of the Assent Form, I found that it was only useful for one of the patient participants with whom I was able to go through the protocol. For the other patient participants, the Assent Form was difficult to use effectively, especially for those who had challenges with English or could not verbalize. Accordingly, I contacted the Ethics Board explaining the challenges and put in an amendment regarding Assent in my application. This clarified that for those for whom the Assent Form was not helpful, I would be attentive to body language and how participants were reacting to my presence as a way to determine that they were assenting to ongoing observations. I also would observe carefully for signs of dissent and apparent discomfort related to my presence as an observer, such as frowning and other apparent

physical indices of concern. I would document assent at each of my visits in my field notes. This was acceptable to the Ethics Board and I was able to continue with my data collection.

On the most part, I found that I was clearly able to receive assent from all patient participants. For instance, patients would smile and nod at me when I asked if I could be present, several would reach out to grasp my hands and pat the chairs next to them inviting me to sit down. On a few occasions, I observed what I took to be dissent, when it seemed that participants were not in the mood to have me present. When this occurred, I would usually observe that a participant would exhibit certain signs of discomfort or agitation, such as by banging their fists on their chair's tray, and I would promptly cease my observations, explaining that I would come to visit them another time. On some occasions, I would arrive to visit with a participant to find them asleep, and in these cases would not be able to determine assent. If this was the case, I would try to sit behind the bed's curtain to provide privacy until they woke up. At other times, participants would fall asleep after I had determined assent, and I would continue to sit with them and observe what was happening around them during these times. However, if they awoke and seemed uncomfortable with my continued presence, I would then leave.

#### **4.5.2 Data collection with family member participants**

Data collection with family member participants involved one-on-one semi-structured interviews, asking open-ended questions prepared in advanced (Richards & Morse, 2013). I utilized an interview guide (See Appendix I) in order to facilitate a comfortable interaction that still allowed for flexibility in responding to participants' comments. This provided guidance for each interview but also allowed for the opportunity to explore new and possibly interesting avenues of inquiry depending on what participants said. Interviews took place in a location of the participants' choosing ranging from the patient's bedside to the hospital cafeteria. One interview

was conducted over the phone. Interviews ranged from 20 to 60 minutes depending on how long the participants felt up to talking. I asked open-ended questions about their perceptions of their family member's experience as an ALC patient. These interviews focused on the first-hand knowledge of their family member, how they thought the person experienced their hospitalization, and specific events or observations they wanted to talk about that pertained to the experience of being an ALC patient and that somehow captured the care they received. Interviews were audio-tapped and later transcribed verbatim by a professional transcriptionist for three of the interviews. Three of the six family member participants did not want their interviews audio-tapped but were comfortable with me taking notes during our interview. All of the family member participants signed consent forms prior to the interviews (See Appendix J). All participants were formally interviewed once only, although I had several informal conversations with family members during participant observations that were recorded in my field notes.

#### **4.5.3 Data collection with nurse participants**

Data collection with the nurse participants also involved one-on-one semi-structured interviews, prior to which the nurses signed consent forms (See Appendix K). Interviews lasted from 20 to 60 minutes. I asked open-ended questions about what they had noticed and experienced caring for ALC patients living with dementia and what they thought the ALC experience is like for their patients. I also used an interview guide in a similar manner as described above (See Appendix L). These interviews were similarly audio-tapped and transcribed verbatim by a professional transcriptionist. Two interviews were not audio-tapped; one because it was hard to find the time to sit down together and we had a more informal conversation where I took notes, while the other interview was not taped as per the nurse's preference. All nurse participants were interviewed once only.

#### **4.5.4 General observations**

I also engaged in general observations whenever I could, paying attention to the ebb and flow of the units. These general observations most often occurred as I spent time with the patient participants, especially during the times that I spent sitting with them in hallways or by nursing stations. For example, I might pay attention to the activity occurring at the nursing station while sitting with a participant who was having a nap in his chair in the hallway. Similarly, there might be something occurring in a patient's room that was worth paying attention to while spending time with a participant. These observations are subsumed into the 100 hours I spent with the patients, and are detailed in the field notes I took during these times. However, I also spent short periods of time, often before and after observation sessions, walking through the units and attending to the general atmosphere of each location. This helped to gain a sense of the greater environment that the patients found themselves in, and these observations are also detailed in the participant observation field notes.

One of the challenges of observational work that is worth mentioning here is that there were often individuals in the general milieu where I was spending time with patients who were not directly participating in the study. This included patients, nurses and other health care professionals, and visitors. The units were busy locations, and the number of individuals who interacted with others and with the patient participants during observations periods was substantial. As such, it was not realistic to obtain consent from each of these individuals, particularly when considering that many of the interactions I observed occurred in open and public settings such as when I was sitting in hallways with patients (Murphy & Dingwall, 2007; Watts, 2011). While it might not be expected that consent for all of these individuals could be obtained, there were still important ethical considerations to pay attention to in these instances,

such as protecting privacy and confidentiality at all times, and being transparent and open about the research being undertaken (Tri-Council Policy Statement, 2018).

In accordance with this, I provided posters to the PCCs of all three units (See Appendix M) that included my name and picture, as well as information about the research project. The posters explained that I would be conducting research on the units and that all collected data would be confidential and would not identify anyone. I also wore a name tag during all of my time on the units that identified me as a researcher. Interestingly, I was often confused for a social worker when I sat with patients, despite the name tag I was wearing. When this occurred, I would openly identify myself as a researcher and explain that I was “spending time” with the participant. On other occasions, I was recognised as a researcher from the poster, and staff and visitors would come up to me to say hello and ask me about my research. In these instances, I would provide general information about the project, but would not share any particularities about the participant I was spending time with.

I also attended patient rounds on four different occasions, attended two meetings where ALC patients were discussed, and sat in on a music therapy session one afternoon. These additional observations totaled 6 hours of field work. During these specific observations, I would take careful field notes recording what I was observing and hearing. At the beginning of the patient rounds and meetings, I always introduced myself as a researcher and explained that I would be taking notes but would not be recording any information that could identify anyone. I also asked for and received verbal consent from all attendees to remain present and to take notes prior to each of these meetings.

## 4.6 Reflexivity

Overall, it is important to assess one's own motivations and biases throughout the entirety of the research process (Tracy, 2010). As Cruz and Higginbottom (2013) state, "reflexivity is focused on making explicit and transparent the effect of the researcher, methodology and tools of data collection on the process of the research and the research findings" (p. 42). I regularly recorded my observations and thoughts in a reflexive journal after my observation sessions and interviews in order to keep track of insights and ideas that emerged from these interactions. These journal entries were instrumental in helping me to maintain a reflexive stance throughout the research process as I explored how I situated myself as a researcher in the context of this study. Regular journaling also helped me to think carefully about how I was approaching data collection, as well as all of my interactions as a researcher in the field. By engaging in reflexivity, I was able to reflect on how I acted, what I was thinking, and consider the expectations and assumptions I brought to this study (Darawsheh, 2014). I also continued to journal during the data analysis phase. I often wrestled with my stances and perspectives as a nurse and researcher, questioning whether my nursing experience affected my judgement and decisions as a researcher. I also reflected on my positionality as a nurse and researcher, and how that could have affected my interactions with the patient participants (Berger, 2015).

As Bartlett & O'Connor (2010) explain, a social citizenship perspective recognizes that the person living with dementia is "a partner and resource rather than simply an individual carrier of problems who must be 'helped'" (p. 81). Recognizing patients as partners and resources, rather than people who need to be passively cared for or involved in research, was a significant shift for me as a nurse. I do approach my nursing work with the goal of promoting a common good, maintaining dignity for patients, and overall contributing to health and wellbeing. However, I

realized that as a long-time nurse, I was very comfortable in my role as the experienced health care professional who knows what to do or say, and who expects to be listened to. Patients, especially in hospital settings, are not normally seen or treated as partners or resources in care. Rather, it is more common to care for and “do for” patients, informing them of what to expect and what to do, and expecting them to conform to routines and expectations. Overall, I am increasingly cognizant that as a health care professional, I wield a certain amount of power over the people I am caring for. Thus, it was important for me to take the time to reflexively consider the power I have over others as a nurse and researcher, as well as think about the inherent power structures that exist within the environments that I am used to working in and that could affect patients who live with dementia. Certainly, this was a critical and ongoing reflexive exercise that I engaged in throughout the entirety of this project.

#### **4.7 Management of Data and Consent Forms**

All audio recordings of interviews and associated transcripts, as well as my transcribed field notes have been stored in a password secure file on my computer that only I am able to access. Each transcript and recording is identifiable by a number only. I have not used anyone’s name in my field notes, identifying people by pseudonyms only. Copies of consent forms, which include the participants’ full names, have been kept separately in a locked file cabinet in the office of my home, and accessible only to me. The notebooks in which I recorded my field notes and reflexive journal entries are also locked in the file cabinet. Data from this project will be kept for a period of five years for possible future research use.

## 4.8 Data Analysis

Data analysis in an ID study is an inductive process that involves looking beyond what seems obvious (Bright, Kayes, McCann & McPherson, 2013; Stephens, 2018; Thorne, 2016). In fact, analysis of data means getting to know one's data intimately and "dwelling in it repeatedly and purposefully and developing a relationship with it" (Thorne, 2016, p. 167). Thus, I started the analysis process by immersing myself in the data by reading and re-reading field notes and transcripts and reviewing my reflexive journal. At this stage in the analysis process, Thorne (2016) cautions researchers not to get fixated on initial impressions. I do not think that one's immediate ideas or thoughts are necessarily problematic or a bad thing in the early stages of analysis. However, it is important to be clear that they are simply one's first impressions, a starting point and definitely not the end product. As such, the analyst should be cautious to not begin coding too early in the process (Truant, 2018). Thus, in the initial stages of analysis, I highlighted passages and sections of my field notes and transcripts but did not specifically engage in any coding. Thorne (2016) recommends the use of a blank notebook, what she calls an analytic notebook, where the researcher can jot down notes and the beginning of ideas during this phase of analysis. Accordingly, I created a password protected file in my computer where I would write down ideas and thoughts as I worked through the analysis process.

After I spent time becoming familiar with the data by taking notes and writing short memos, I entered all of my data into Atlas.ti, a software program that helped me to organize my data and which I used to create initial codes that broadly encompassed the ideas and patterns I was picking up on. As Thorne (2016) explains,

...the initial code is creating a mechanism by which you can bring together a group of data bits that *might* be thematically related (or might not) so that you can

interrogate those pieces of data as an evolving collective whole, as well as continuing to ask questions about the relationship it might have to other aspects of your unfolding understanding of your data set (p. 160).

It was important to not get too excited about data that seemed to be significant at this point, keeping in mind that the analysis process was still evolving. Thorne's use of the word *interrogate* above is a reminder that analysis is a distinctly inquisitive activity, a process of repeatedly asking oneself questions about the data and what one might be seeing in terms of patterns. It is also an iterative process of challenging oneself about possible alternatives, what Thorne (2016) calls "allowing your thinking to move back and forth between the parts and the whole" (p. 177). From my point of view, I approached this as trying to understand what different parts of a pattern I might be noticing meant on their own, as well as relative to one another (Edwards, McClement & Read, 2013). This was quite an expansive process at this point, as I ultimately ended up with just under 700 codes, many of them variations of the same ideas.

As ideas and patterns started to form, I had to make sure that they aligned with the research question that began this whole process. This was about challenging what I thought I was seeing in the data in terms of relationships and patterns, while making sure that I was also seeing what was emerging in analysis within the greater context and purpose of the study (Thorne, 2016). This is quite important in an ID study as it links the researcher back to the goal of ID work, in that the results of analysis should be meaningful to applied settings and disciplinary knowledge. However, it was also essential for me to remain aware of how I have been socialized as a nurse and how I think as a nurse, to make sure that I remained open to analytic possibilities that I might otherwise miss out on if I became too focused on the study's disciplinary orientation. It was challenging to remain both grounded in my disciplinary outlook, but also not too bound by

it at the same time. Along with my disciplinary perspective, I was also influenced by the theoretical lenses of personhood and social citizenship that were significant underpinnings of this study. It was important that I remember that the data that I was considering represented the experiences of people, and their essential personhood and status as social citizenship was always at the forefront of my mind. As such it was helpful for me to journal regularly about how I was managing and finding this process of interpreting data, while integrating the disciplinary and theoretical perspectives that I brought to the study, during the analysis phase of this study.

In the end, the goal of analysis was to move beyond what seemed obvious and to move in the direction where interpretations and conceptual claims could start to evolve (Thorne, 2016). In qualitative work, recognizing patterns and simply “theming” data is insufficient for developing rigorous work and meaningful knowledge (Thorne, 2020). As such, the evolution in my analysis was a lengthy process where I utilized strategies such as mapping my ideas out on a large piece of poster paper, which I later condensed into smaller separate pieces of paper. It was helpful and crucial to remain focused on the study’s research question, which helped to put me back on track if I found myself exploring ideas that were interesting, but did not necessarily align with the project’s goal. I also engaged in discussion with my supervisor and committee members about the course and progress of my analysis, which was valuable and helped to push my thinking and explore different ways of considering my findings. Overall, there certainly was a process of trial and error, as I considered where the interpretation and synthesis of the data was going, stopping and restarting several times. Eventually I decided on three main threads of analytic results to focus on, which are presented in the upcoming three Findings chapters.

## **4.9 Presentation of Findings**

Findings in this dissertation are primarily presented in a thematic format, bolstered with transcript and field note extracts. In the end, writing up the findings can be considered as the final interpretative step, where all of the information that has been amassed throughout the research process is incorporated into an organic and meaningful written account. Certainly, the writing process served to refine the data analysis process for as I began to write my findings chapters, I was able to re-examine certain ways that I had considered my data and re-work some of the findings in ways that became more meaningful and coherent. I have also included a few illustrations that I created based on my fieldnotes, to help provide further context and depth to the written work.

### **4.9.1 Found poetry**

As a way to further represent the ALC experience, I have included found poetry as part of my presentation of findings. These poems are included in the Prelude, Interludes and Epilogue sections of this document. Poetry has been described as a tool that facilitates connections between the writer and the reader, and in doing so make research findings more accessible to others (Lahman, 2011; Reilly, Lee, Laux & Robitaille, 2018). Found poems are created with words and phrases, as well as entire passages, from other sources such as interview transcripts, and reformulating them into poetry (Butler-Kisber, 2002; Reilly, 2013). Overall, found poems are created solely from the data that has been collected (Lahman, 2011), and is a “process of intuitively sorting out words, phrases, sentences, and passages that synthesize meaning from the prose in the light of a particular research question” (Prendergast, 2006, p.370).

For the poems in this dissertation, I utilized words and phrases from my field notes as the basis from which to build found poems, along with words and phrases from the one semi-

structured patient interview that was conducted. According to the website *The Found Poetry Review* (2016), there are several types of methods one can use to create found poetry. I have used what the website calls “Free-form excerpting and remixing”, which involves rearranging words and phrases from other sources into a poem. Eight poems have been included, one for each of the eight patient participants in this study. I wrote the poems after I completed data analysis and had written the findings chapters, with the intention of honouring each of the patient participants, separate from the data in the findings chapters. I offer these poems as short and evocative vignettes, affording additional glimpses into the patients’ subjective experiences and perspectives. I purposely begin and end this dissertation with a poem, with the intention of highlighting that this study is about the patients’ experiences. Similarly, the interlude poems are oriented to offer the reader a pause and an opportunity to reflect on what the patients have experienced.

#### **4.10 Ensuring Rigour and Credibility**

How accurately a phenomenon and experience have been interpretatively represented is a potential concern in any qualitative work. However, as the goal of qualitative research is to understand and explain rather than measure a phenomenon (Pyett, 2003), it is incumbent on the researcher to demonstrate that the process leading up to the final interpretations was conducted in a way that allowed for credible results. Within the qualitative research field, several scholars have developed frameworks from which to evaluate the quality and rigour of qualitative research (eg: Yardley, 2000; Tracy 2010; Thorne; 2016). Thorne has included a discussion in her 2016 ID book in regards to how ID researchers can “articulate the intricate blend of artistry and the science that interpretive description represents, and thereby render that distinctive perspective

increasingly meaningful within the evidentiary context of our practice disciplines” (p. 232). As such, I have drawn on the criteria from Thorne’s book as a means by which to consider the rigorousness and credibility of the work that has come out of this study.

#### **4.10.1 Epistemological integrity**

Thorne (2016) discusses the epistemological integrity of qualitative research whereby there is a coherent connection between the research question, the chosen design, and the researcher’s assumptions about the nature of knowledge. As this was an ID study, where the goal was to develop disciplinary knowledge that would be useful and applicable, there was a clarity of purpose from the beginning of this undertaking: the development of nursing knowledge that would help to improve the care of ALC patients living with dementia. I approached the research process with the understanding that nursing knowledge is complex and can take many forms, reflecting the complexity and richness that is nursing practice and the world of patient care. In accordance with this understanding, the methods I chose during data collection from conversations and interviews with patients, family members and nurses, to observations on the wards in varied circumstances, allowed for the complex experience I was interested in to be examined in different ways.

In addition, from an epistemological stand point, I was very clear that there was valuable knowledge to be gained from approaching the inquiry process from the perspective of the patients themselves. My commitment to bringing the patients’ subjective experiences to the fore was a crucial lodestone that kept me on track throughout the study, from data collection to analysis to presentation of findings, ensuring that the knowledge that came out of this work was based on what could be revealed about their subjective experiences. I think that this was a strength in this study, not only because the experiences of those living with dementia are not

taken into account often enough, but also because of what we have learned directly from them about how to improve care.

#### **4.10.2 Representative credibility**

While the goal was to shed light on the patients' experiences and perspectives, which meant that the bulk of the data came from the patients themselves, the complexity and multi-layered nature of their hospitalizations was further revealed by incorporating data from family members and nurses. As Thorne (2016) explains, "to convey substantive completeness, we expect that qualitative researchers recognize knowledge beyond a single angle of vision..." (p. 234). It was helpful to expand my "angle of vision" by involving family members and nurses in the study, while remaining committed to the perspective of the patients. While I would not be so bold as to claim that the participants who took part in this study are representative of the totality of the ALC experience, especially for those living with dementia, I feel that the rich and varied data that came out of data collection with all of the study's participants have helped to establish a clear and credible representation of what ALC hospitalization can be like for patients.

The sample of patient participants also included eight very different individuals, providing an example of the variability amongst people who can be designated ALC in our hospital systems. Again, I would not claim that the participants in this study are representative of all ALC patients who live with dementia. However, their different backgrounds and circumstances, combined with the shared commonality of their experiences in hospital, provide a credible representation of the phenomenon of interest. Of note, I did not member check with the participants following completion of analysis. Member checking is not always congruent with ID studies as interpretive undertakings (Thorne, 2016). In addition, it would have been quite difficult to check back with the patient participants following analysis given that many of the

patients had challenges with communication. While I could have conducted member checking with the nurses and family members who participated in the study, this would not have aligned well with the purpose of this work, which was to illuminate and focus on the patients' experiences and perspectives.

#### **4.10.3 Analytic logic**

As part of ensuring rigour, Thorne (2016) explains that qualitative studies should also exhibit an analytic logic, where “the reasoning of the researcher” (p. 234) is explicitly detailed from start to finish. While the process of inquiry, particularly in qualitative research, can unfold in unexpected ways, the researcher must be able to demonstrate explicitly that there is an inherent logic binding the whole together from beginning to end. When considering the process of building this study, each step was thought out carefully: from my initial musings and literature review, to the theoretical and disciplinary scaffolding integrated within the work, to the methods chosen to collect data leading to the analysis and writing up of the study's findings. When plans had to be altered or adjusted, this was clearly explained in this dissertation, along with the reasoning and rationale for any changes, creating an audit trail that could if necessary be followed by another researcher. I also utilized a journal during data collection and analysis to record and explore the decisions I made as a way to map and track the steps I took. Furthermore, I have supported my findings with numerous excerpts from my field notes and verbatim quotes from my interviews, grounding my interpretive claims (Thorne, 2016) in the data from which they were derived.

#### **4.10.4 Interpretive authority**

As Thorne (2016) explains, “While we recognize that all knowledge is perspectival, we need assurance that a researcher's interpretations are trustworthy, that they fairly illustrate or

reveal some truth external to his or her own bias or experience” (p. 235). I engaged in a reflexive process throughout the data collection and analysis phases of this research as a way of consistently examining any biases that I could be holding onto that might affect the outcomes of this study. This was done with the use of reflexive journal writing after most of my observation sessions, as well as during the period of time when I analyzing the data that I had accrued. I also discussed my interpretations with my supervisor and committee members at several points in time, during both the data collection and analysis stages of the study.

It was important that the thematic findings were as focused as much as possible on the patients’ perspectives, and I used first-person language to describe the main themes whenever I could. I recognize that as the researcher the findings are ultimately my interpretation of the data. However, I tried whenever possible to separate my assumptions from the patients’ accounts, and to be accountable to the purpose of the research and to the patients who participated in this study. While I collected and analyzed the data, and acknowledge that my own perspective almost certainly affected this process at times, ultimately this was their story in the end, not mine.

#### **4.10.5 Additional considerations**

Apart from the criteria discussed above, I would like to address the moral defensibility (Thorne, 2016) of this work, especially as the study delved into quite sensitive topics such as living with dementia, the stigma that can accompany this lived experience, and the distress that the patient participants experienced as part of their hospitalizations. These are challenging subjects and experiences to inquire into and to dissect, while ensuring that the people whose experiences are being scrutinized are protected and not taken advantage of. Observing and detailing the distress that the patients experienced was challenging. It was also hard to witness

and describe some of the practices that contributed to the patients' distress. What the patients and family members shared by participating in this study deserve acknowledgment and gratitude.

As a nurse myself, my goal was not to denounce or criticize nurses, or to condemn outright the health care system. Rather, it was to explore, reconsider, and challenge the nursing role and current system of care in light of what we can learn from those who provide us with the opportunity to work in health care and nursing in the first place. In terms of nursing practice, what can be learned from the patients can cause discomfort and concern as the findings in the following chapters encourage reflection on the care they receive in hospitals. However, these are important findings that bring attention to what the patients are experiencing, providing the basis for considerations on how as nurses we can do better.

#### **4.11 Clarification of Language Use**

While the findings are the result of my interpretive work as the analyst, many of the themes and accompanying sub-themes have been written in the first person. It is not my intention to co-opt the patients' experiences by using first-person language. Rather, I aim to bring to the fore whenever possible, their first-hand accounts. As such, the findings chapters focus foremost on analysis of patient participant data, as this is the story of ALC patients living with dementia, particularly of the eight patient participants who took part in the study. In the three findings chapters, the eight participants are identified by pseudonyms, which are in no particular order: Mrs. Wong, Mr. Lee, Mrs. Ho, Mr. Powell, Mrs. Rogers, Mr. Hastings and Mr. and Mrs. Chiang.

I have also drawn upon information provided by the nurse and family member participants when it serves to add depth and context to the patient participants' experiences, and to the greater experience of ALC patients living with dementia. At times, I identify family

members by their relationship to the patients, but I do not refer to them by name. In other instances, numbers are used to identify family members, particularly if I am providing a direct quote from their interviews. Nurses are also identified by participant numbers in this study. I have not provided pseudonyms when including data from family members and nurses, not because their contributions and perspectives are not valuable, but because this is a study that is meant to focus on the patients' perspectives and experiences. Up to this point and throughout the following chapters, I often refer to the patient participants as "the patients". To be clear, this is not meant to pigeon-hole them solely into the role of patients, nor overlook who they are as whole persons. Rather, I use the term in accordance with the purpose of this dissertation, to illuminate the patient experience. Certainly, it is not my intent to further label them.

#### **4.12 Chapter Summary**

This chapter has focused on the methods undertaken as part of this ID study. The sample, recruitment, and data collection methods, as well as the analysis process have been discussed. In addition, I discussed how I undertook a rigorous study. This chapter also brings to a close the first part of this dissertation. The following sections of this dissertation bring us to the core of this research project and focuses on what has come out of the process of data collection and analysis: the study's findings.

## Interlude II

### Wisdom and Perspective<sup>3</sup>

I ask him what it has been like for him  
To be in hospital and he asks me,  
“Am I going to be pissed about it?  
What would that do?”

He tells me how he underwent business  
And management training years ago  
I ask him what makes a good salesperson  
And he tells me, “listening”.

He feels he is being sent to a care home  
Because he is still “wobbly” when he walks  
“Wobble is the way of life,”  
He says philosophically

He does admit to feeling frustrated at times  
As he would prefer to be home  
I ask him to describe himself using an adjective  
And he tells me that “I’m just [me]”

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<sup>3</sup> Written with excerpts from Field Notes for Mr. Hastings 01.14.2020-01.28.2020

## **Chapter 5: Providing Context**

### **5.1 Chapter Overview**

I have included this chapter as a useful and contextual bridge to the study's main findings. As discussed in the previous chapter, I sat in on meetings where ALC patients were discussed, and recorded what I observed in my field notes. In addition, as part of my interviews with nursing participants who worked in leadership positions, I asked questions about the ALC designation process in the hospital setting where I was conducting my research. In so doing, I gained important insights into the system that provides care for ALC patients, and describe these details below providing background context to situate the main findings that follow.

### **5.2 The Process of ALC Designation**

As it was explained to me by PCCs who participated in this study, patients have to be medically stable to be designated ALC, which means that they do not require daily blood work, intravenous medications or have a need to be actively rehabilitated. I was told that a list of currently designated ALC patients is maintained in the hospital's tracking system. The doctor overseeing the patient's care usually orders that a patient be designated ALC. In some cases, the PCC can ask the doctor to designate a person ALC if they feel that the person meets the criteria. It is assumed when a patient is designated ALC, that if a facility bed were to come available or alternate care arrangements were put in place, that the person would be ready to leave hospital the next day. However, if a patient's condition were to change and they needed to be seen by a

doctor every day, and required regular symptom and clinical management, they would no longer be considered ALC. As one of the nurses [N2] explained:

Say somebody was ALC and they got a UTI....Now if they're just on PO antibiotics and they're not really that sick, I wouldn't take them off the list....Now, that being said, if they're like acutely delirious and confused and having lots of symptom management because of it even on PO, then I would take them off the ALC list because then the doctor needs to see them every day and there's more management involved.

Sometimes patients will become acutely ill, but do not come off the ALC list. According to one of the nurses [N4], "It's not always clean data" when it comes to who is designated or not. This seemed to be the case for one of the patient participants who was never officially designated ALC, but who was designated No Home First (NHF). Patients usually are initially designated NHF as a precursor to ALC designation. For a patient to be considered NHF, all possible discharge options have to first be considered and explored with the patient and family. Once it is clear that a patient cannot be discharged home, the transition nurse who normally coordinates Home Health Services, must present the patient's case to the hospital's leadership team for NHF approval. As it was explained to me, "We have to write up a summary and then we e-mail to all the directors across the hospital or in the panel and every Friday, late afternoon, and then we have the meeting the following Tuesday morning." [N3]. It seemed that once a person was deemed NHF, then ALC designation could proceed, as long as the person was no longer acutely ill.

Some of the discrepancies in designation that can occur with ALC designation were attributed to lack of experience in some staff who were still learning about the ALC process or who may have not had the chance to remind physicians to indicate in the chart that a patient

should now be considered ALC. In other instances, ALC designation could be delayed when wards were busy or when certain staff who normally followed up with ensuring patients are designated were away. Also, a patient may be deemed NHF, but for a variety of reasons, such as ongoing complex care needs, many not end up being designated ALC.

### **5.3 The Specifics of ALC Coding**

Once a patient is designated as ALC, further (more specific) designation occurs, in terms of the patient's needs and likely discharge destination. As one of the nurses revealed in an interview:

There are lots of ALC designations. The biggest bucket of ALC which is Alternate level of Care is really the patients that are waiting for residential care...But there are other ALC designations when we say a patient may require housing for instance. If they come in and they have no fixed address, you need to go to another...so that's another example. Mental Health, Tertiary care, those are...Special care, like ALC has definitely, obviously a number of different sorts of destinations. But really, ALC as a whole, when you look at ALC as a concept, it's really saying that the patients themselves don't need acute care needs. [N7]

These permutations in ALC designation relate to the specific coding that is used within the hospital tracking system. In fact, patients could be associated with a range of ALC codes from AL0 to AL11. A list of the ALC codes has been included in Appendix N. The specific AL codes designating patients in the hospital's tracking system were not discussed on the hospital units amongst front-line staff, where patients were simply known as ALC. However, behind the

scenes, patients could be designated with variations of the AL code throughout the period of their hospitalization. This specific coding process was explained to me:

So typically what could happen is that the...and what should happen is that the PCC or the unit clerk, one or the other, the PCC will say, okay, you know, Mr. Smith is now AL10 which is we think his trajectory more than likely is going to be long term care....Fine. So we put him as AL10. For anyone else, they say well okay, he's not going to be long term care but we don't know where Mr. Smith's going to go. He becomes an AL11. [N7]

Thus, an ALC patient could be associated with different AL codes, and these could vary and change depending on fluctuating needs and discharge plans.

#### **5.4 Patient Rounds and Meetings**

On the units, all patients are discussed in daily patient rounds. Usually, there would be "ALC" written next to the names of designated patients on the patient board that is used to track information during rounds. I observed that discussion in rounds concerned with the care of ALC patients were usually quite brief. This is illustrated in the following field note:

Rounds on this unit have the primary nurses taking their turns to report in at rounds to the team gathered. The PCC, TN, rehab staff are present. Patients who are designated ALC have the letters ALC written next to their names, often there is also no HF (no home first) written on the board. Some ALC patients are waiting for home support. Impressions: rounds consist of a very basic overview of patients' standings. Things that are reported include their work up schedule, including tests that need to be done, their estimated date of discharge, and whether someone is on IV medication. When it comes to patients who are ALC, reporting on their status is extremely basic. For example: the PCC will ask if he or she is okay? These are the responses I overheard: "Stable." "Yes!" "Usual." "Usual Behaviour" [FN: 10.23.2019]

Other discussion that might occur during rounds for ALC patients tended to revolve around updates regarding discharge planning. However, it was interesting and revealing that reports

from nurses about ALC patients during daily patient rounds tended to be quite sparse, with most of the discussion during these meetings revolving around non-ALC patients and their acute care needs.

The hospital where the study took place also had weekly meetings where team leaders from the different units, usually PCCs, would come to report on patients who had been in hospital for long stays. These were called Long Length of Stay (LLOS) meetings and were normally attended by the leadership team of the hospital, including the acute care director and director of patient flow. Patients who had been in hospital more than 15 days were classified as LLOS patients. As I was told:

...but you know, in patient flow world, we know that you know, a typical length of stay is you know, it varies but for...average length of stay for all patients is between six and eight days. So if someone is here for 15 days, they're an outlier." [N7]

I sat in on one of the LLOS meetings and observed that representatives from the different units would come to the meeting at successive times to report on any LLOS patients.

An excel worksheet appears to be used during each of these meetings, that is added to constantly and shows the patient name, diagnosis, whether they are ALC or not ALC, physician and length of stay. Issues that are preventing discharge planning, and other important discharge notes are also included. It seems that the length of stay is indicated as follows: 15 to 20 days, 21 to 30 days, and over 30 days. From this, I surmise that a long length of stay is anything over 15 days of hospitalization.

Throughout the meeting, representatives from three of the units (the ones I've been observing on) come at successive times, and the team as a whole go through the long length of stay patients. Focus seems to be on disposition planning, communication strategies with families and patients, whether someone should be on the ALC list, and why someone has come off the ALC list. The patient care coordinator will give an update of their acute-care needs. When the team asks whether someone should be on the ALC list, the patient care coordinator will say "not quite yet" if there are still some medical concerns ongoing. [FN: 11.26.2019]

As the field note excerpt above shows, focus in the LLOS meeting tended to be on disposition planning, in terms of what could be arranged for the patients' future discharge, and the

identification of any barriers to discharge. ALC patients are also discussed at this meeting, as all ALC patients tend to be LLOS as well. I noticed that most of the patients discussed in the meeting were elderly, many in their 80s and 90s, with most having complex needs. As such, much of the discussion about them revolved around planning for complicated discharges home or discussing what types of care facilities might be appropriate for them.

I also attended an ALC meeting, which is held twice a week to specifically discuss all ALC patients currently in hospital. The following field note describes what I observed:

Various leaders are present, the meeting is being led by the patient flow manager. The directors for Home and Community and for Acute Care are present. Managers for the various sites and services are also present. The PCCs and transition nurses are not at this meeting... During the meeting, all patients who are ALC are discussed one at a time. This appears to be a meeting about reporting on current status, as well as discussing ideas on how to move patients on from hospital. When it comes to discussing home versus facility, I hear questions such as “Are supports in place for home support, for home equipment?” I sense that part of the ongoing tensions include managing the differences between what families want and expect, and what is available. I hear the acronym AAP frequently. This means that the patient has been assessed and is awaiting placement. Basically this means that the paper work has been done including the MDS and the financial assessment. I suspect that someone becomes AAP after it has been determined that they are no longer “Home First”. It is apparent that the process becomes complex when there is no family and the Public Guardian and Trustee has to become involved. As such, it is also apparent that consent processes are complicated. It is also important to note that patients who have been designated ALC in other hospitals can be repatriated here, to wait in the hospital situated in their own community. [FN: 10.24.2019]

While LLOS stay meetings were focused on what was happening in acute care, the ALC meeting also involved representatives from home and community services. This wider representation of services at the meeting reflects that ALC patients’ ongoing needs, and the resources required to meet them, now lie outside of the hospital setting.

I was told by a nurse leader that while there might be slight differences in procedures between different hospital sites, that the ALC processes discussed above are similar to what many hospital teams would follow. Of interest, the bulk of my data collection was completed just

prior to restrictions imposed by the COVID-19 pandemic. I was told that the ALC rates had dropped in the study setting since the onset of the pandemic in BC, not because many ALC patients had been quickly sent to various facilities as in the case of provinces like Ontario, but because hospitalization rates and emergency room admissions had declined significantly. Overall, I realized that there were many ways that ALC patients were tracked, discussed and followed up with at this hospital site, an interesting and illuminating glimpse into the system and processes in place that act as important context for the experiences of ALC patients.

## **5.5 Chapter Summary**

In this chapter, I have provided useful context and background, in terms of the processes that take place in regards to ALC designation and discharge planning in the hospital site where this research took place. This chapter has also set the stage for presenting the findings that have come out of collecting and analyzing the data. I further set the scene for the following findings chapters with a quote from one of the nurse leaders I interviewed. This quote illustrates that while there can be good reasons for weekly meetings and the coding of patients in tracking systems, these processes do not address the specific care needs of patients while they wait in hospital:

Yeah, I think that sometimes we don't give ALC patients enough attention...I think that there's this perception that because they're no longer acute...designated acute, that they don't need the level of care that other people who need acute care services. And the reason I say that is because there's been...and this is not reflective of poor nursing or whatever, but I think that they kind of get lost. They kind of get pushed to the back and patients with acute needs and IV meds and this and that have the focus. [N7]

In the following three chapters, I present the main findings of this study. In Chapter Six, I consider the daily experience of being an ALC patient living with dementia, utilizing a wide lens to take into account what it means to be a patient waiting for discharge, while considering the chaotic and busy environment that patients wait in, the spaces they inhabit, and how the experience changes for them over time. Chapter Seven is devoted to bringing into sharp relief the distress that ALC patients living with dementia experience on a regular basis, and how their distress is manifested and understood by nurses and other health care professionals as “behaviours”. Finally, Chapter Eight widens the perspective and considers and explores the agency and resiliency of ALC patients, as well as what makes a difference for them during their hospitalizations.

## Interlude III

### When You Hold My Hand<sup>4</sup>

She opens her eyes and mumbles to herself  
Patting her pillows  
She doesn't walk anymore...  
She's been here for seven months

She's sitting up in bed  
Smiling and laughing  
She's happy but "I am tired"...  
Says the husband

She lifts her head every so often  
Looks over at him  
She is drifting off...  
And her husband sits quietly

He perches on the side of the bed  
Calling her by her name  
She perks up immediately...  
They hold hands

She talks often, he says  
She thinks a lot  
But he does not know...  
What she's actually thinking about

He tells me that she responds to him  
That she recognizes his voice  
He softly reassures her  
Holding her hand...

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<sup>4</sup> Written with excerpts from Field Notes for Mrs. Wong 10.24.2019-11.15.2019

## Chapter 6:

### Exploring the Vista – Living and Waiting as an ALC Patient

*It's a long...if my wife goes out somewhere, it's a long, long day, long wait. But you know, there's not much else you can do." (Mr. Powell)*

#### 6.1 Overview

This chapter focuses on the daily experiences of the patient participants, who no longer required regular hospital care, but who found themselves waiting for long periods of time on hospital wards, an environment that presented several challenges for them. The following pages explore how the patients experienced the hospital setting from hectic early morning routines to the drawn-out times in-between care interactions, when there was not much for them to do. In one sense, the patients experienced a static hospitalization in that they waited for their discharge destination to be arranged, and for long stretches of time not much seemed to be happening or changing for them. However, as it is revealed in this chapter, they experienced changes in their health and wellbeing over time, some that were quite sudden while others were subtle and occurred gradually. In addition, for patients not going home, the transition in living arrangements and care could be sudden and abrupt, and difficult to prepare for. Overall, this chapter is focused on three main thematic accounts that reveal the patients' ALC hospitalization experience: Home...but Not Home, the In-Between Times, and While I Wait Things Can Change.

#### 6.2 Home...but Not Home

Early on in my observations, I was sitting with one of the patient participants in a four-bed room, it was late in the morning and the room was quiet as many of the room's occupants were napping, while another patient's television was playing in the background. I was struck by

the atmosphere of the room and by some of the sounds I was hearing that were somewhat home-like, but which contrasted sharply with other aspects of the immediate environment, which swiftly reminded me that I was in a hospital. I made the following observation in my field notes:

The TV is now spewing commercials, fast food and other ads...it's in some ways just like sitting in the house (anyone's house) with everyday background noise at times. Snores as if my husband is napping on the couch. But it's not home-like really, especially as there is a fourth announcement for announcing I-care rounds, and static on the PA system as there is someone saying "Hello, Hello?" [FN: 10.24.2019]

At this point, I was spending time with Mrs. Wong who had been designated ALC for over eight months and her corner of the shared hospital room was effectively her temporary home as she waited for a facility bed. The theme of Home...but Not Home reflects the fact that many ALC patients are waiting long periods of time in hospital, either waiting to return home with enhanced supports, or as is more often the case, waiting for a new home, specifically in a long-term care facility. In a way, the hospital becomes an alternate version of home, as patients and their family members attempt to find normalcy and a routine of daily life within a challenging and busy setting, that is not really set up to provide the sense of daily home-like living. Many of the patient participants who were able to converse with me told me that they would rather be home, an unsurprising sentiment for a person in hospital, but a particularly poignant one when considering that majority of these individuals were waiting for facility care and would not be returning to their homes. Overall, this theme demonstrates the challenges of dwelling long-term in a shared space that is busy, often chaotic, and not easy to navigate.

### **6.2.1 Such a busy place**

That the hospital is a busy, and frequently a chaotic environment is not surprising, but this reality takes on additional significance when considering what the experience must be like for people living with dementia. Many of the patient participants I spent time with were easily

confused, and the daily routine of the hospital was not always easy for them to deal with. Generally, there is always a lot going on in a hospital unit, even for ALC patients who do not require the scale of hands on care that non-ALC patients have need of. For instance, despite their ALC status, the patient participants I spent time with required regular vitals monitoring, usually once per 12-hour nursing shift. I noticed that this could be a bewildering or disruptive experience for patients, particularly in the early mornings when patients had to be woken from their sleep, in order to have their vitals taken and recorded.

The nurse comes in to take vitals for all of the patients in the room. Mr. Lee is still asleep and she says “good morning papa” as she prepares to take his blood pressure. He rouses and utters his usual guttural cry. The nurse gently shushes him, and says “it’s okay.” She asks him if she can take his temperature saying, “can I take your temperature sir?” He cries out once or twice more as she finishes. [FN: 11.15.2019]

The student nurse comes in to take Mrs. Rogers vitals. He turns on the overhead light and says good morning. He asks her how she’s doing. She says, “I don’t know yet.” He’s asking her questions about her name, date of birth but her voice fades away as she attempts to answer. I think she has fallen asleep again. [FN: 11.21.2019]

Apart from vitals, the daily schedule of a hospital ward revolves around other regular routines and events, such as mealtimes, that can affect how and when care is delivered. This was particularly the case in the early mornings when nursing staff worked swiftly to get patients up and washed in time for the breakfast meal. Some of the units were more flexible than others in terms of letting patients sleep in, but as many of the ALC patients living with dementia wore incontinence pads, it was important to change and wash them earlier rather than later, to maintain skin integrity and preserve dignity. This meant that there was often a lot of activity and personal care being provided each morning, swiftly and within a short period of time, in order for patients to be sitting up and ready to partake in their morning meals.

The high level of activity and busy-ness of the hospital units extended beyond the patient rooms. The nursing stations, the main hub of hospital units, are always busy areas, where staff

convene and confer, and where telephones are ringing, supplies are delivered and new patients arrive to be admitted. Several of the participants spent time by nursing stations, and by virtue of this experienced first-hand the busy nature of the wards they were on. Sometimes the chaotic nature of these areas on the units could be a lot to take in for patients experiencing confusion. One afternoon, Mrs. Ho and a fellow patient, another person who seemed to be easily confused, were seated side by side by the nursing station. A television had been placed in front of them and was loudly playing a movie. I recorded the following in my field notes:

I find Mrs. Ho seated next to another patient in an open area in front of the nursing station. They are both in Broda chairs, and they're watching a Christmas movie, the actor Arnold Schwarzenegger appears to be in the movie. I watch her face, she reacts in surprise to something happening on the screen...At one point, she reaches over to the person's tray next to her, wiping at that person's tray with a bit of the edge of her blanket. She starts talking quite loudly, perhaps reacting to something on the screen. The TV is quite loud. She is transfixed by something occurring in the movie but I notice that at other times, her brow is furrowed, and she runs her hands somewhat agitatedly between the wheelchairs. Perhaps there is too much stimulation, I wonder to myself? [FN: 11.14.2019]

Shortly after this observation, which I had observed from afar, I came up and said hello to Mrs. Ho and then joined her and the other patient. Just then, a doctor came up to us and asked the patient sitting next to Mrs. Ho if he could examine her. He started to conduct an eye exam right there, in the hallway, with both Mrs. Ho and I sitting next to her and the TV still on. It was an odd experience, as Mrs. Ho and the other patient were bombarded with stimuli from the nursing station and the movie playing in front of them, all while a physician was conducting an assessment. The doctor was close enough that Mrs. Ho could have reached out her hands to touch him. I remember feeling very uncomfortable and unsure how to parse all the information and stimuli I was taking in, and then considered how confusing this must have been for Mrs. Ho and the patient next to her.

Many of the ward staff that I spoke with acknowledged that ALC patients living with dementia require a certain amount of attention that is not always easy to provide when wards are busy. One of the nurse participants [N6] spoke specifically of the patience nurses require when it comes to care interactions, in terms of being able to take the time needed to provide care to a patient who may be confused and bewildered. However, as she stated, “I feel I’ve lost patience”, indicating that she did not always have the wherewithal to provide the kind of care she felt the patients required. This same participant attributed some of the challenges in providing care on a shortage of nurses. As she put it, there is not enough “manpower” to provide the suitable care that ALC patients require, particularly for those who are more easily confused. She explained that when there are not enough staff, it is hard to toilet people regularly who need help with this task, and nor are there enough people to watch out for patients who wander or might be climbing out of bed. She was an experienced nurse and felt that she had “more time” when she first started nursing to care for patients. As she put it, these days she finds that “it’s always go, go, go, go!”

This sense of always being on the go, and having to respond to many different needs at once, was evident one afternoon when I was spending time with two patient participants in the hallway, and was able to also observe the challenges one of the nurses was experiencing. The following observation concerns Mr. Hastings, who liked to walk around the ward but often could get lost, or try to explore areas of the hospital beyond the unit’s doors.

Mr. Hastings comes out of his room again. “Where are you going?” asks the nurse. “For a walk,” he says. He walks past us, then disappears around the corner. The nurse has been watching by the med cart by the entrance to his room, then follows him when he turns the corner. She redirects him back, as he has been heading for the exit to the ward. He heads down the hall but then turns around and comes back in our direction again. The nurse says, “It depends on the day.” I think she is referring to his wandering. “I can’t do my work!” she also says out loud as she follows him again as he heads for the exit, and then redirects him back to his room. [FN: 01.16.2020]

While this demonstrates the challenges the nurses face, in terms of having to juggle their nursing tasks while watching out for and responding to confused patients, the effect of this constant supervision on patients like Mr. Hastings was also noticeable. I often observed his frustration at being frequently redirected by staff, as well as not being able to wander around as he would have liked. He told me that he did not like that he could not walk around freely and explained that he found the hospital environment quite confusing. Ultimately, he found his way off the unit one morning, and managed to walk into one of the elevators. He was later found on the main floor in another section of the hospital. Later that day, he told me that he had gone for a walk and gotten a bit lost and that he had caused “excitement when walking around”. He did not seem perturbed by this event; in fact he was smiling when he told me about having been off the ward on his own. This was in contrast to the experience of unit staff who had to act quickly when they discovered he was missing off the unit, and found this episode quite stressful and upsetting.

### **6.2.2 Too many hands**

Along with being a busy place, the wards where ALC patients spend so much time were constantly in flux. In particular, staff caring for patients routinely changed as nurses and care aides worked through different rotations. The hospitalists caring for patients also changed routinely, which could be quite confusing for patients and family members. One of the family members [FM5] discussed this specifically and talked about how this was challenging. As she stated, “The other piece was the physician changed every week...because they’re hospitalists...So you never got to speak to the same physician twice.” This was especially concerning for this family member, as she could not follow up with ongoing concerns, as care providers continued to be different week to week.

One of the nurse participants [N6] captured this sense of constantly different staff caring for patients when she stated that “too many hands” are involved in patient care, which she found could be especially confusing for patients living with dementia. I witnessed this idea of “too many hands” one afternoon, when I was sitting with Mrs. Ho. Over the hour and a half period that I spent with her, I noticed that five different staff members came in to provide care. During that time, a geriatrician came in to quickly to check in with her, and a variety of nurses came to her bedside to complete four different tasks: To give her oral medication crushed and mixed in apple sauce, to take a urine sample from her catheter, to empty her Foley catheter bag, and to give her an injection. Surprisingly, Mrs. Ho did not seem upset by the many different care providers who came by, although it might have helped that I was present and sitting by her side throughout all of these interactions. As I observed:

One of the nurses comes in and leaves a Luer lock syringe and some plastic bags on the bed. Mrs. Ho looks at the equipment with some alarm. He comes back in and tells me that he is going to take a urine sample from her Foley bag and starts to reach up her leg for the port...she looks concerned and starts to move her legs. “Don’t kick,” he says...I touch her arm and start to speak in a reassuring voice, explaining that he is going to take a sample and that it won’t hurt her. She looks at me, and the nurse is able to finish drawing the sample, then leaves. Right after this, another nurse comes in to empty her Foley bag and measures the urine output. Shortly after, another nurse (this is the fourth one to come by) comes in with another syringe and says that she has to give her an injection. [FN: 11.12.2019]

After this observation, I considered what it must be like for patients to have to encounter so many different staff, particularly if a patient was not feeling well or having a bad day. While it was a concern for family members to not know who to follow up with or talk to when medical staff were always changing, the frequently changing faces of care providers must have been bewildering at times for patients themselves. When I asked one of the nurse participants [N5] to describe her understanding of patients’ hospital experiences, she encapsulated exactly what Mrs. Ho experienced in the care interactions described above. As this nurse explained:

I mean we are basically taking a person from a normal routine in their normal environment and put them in an environment where the four walls does not look the same to them and we have people coming in now, physicians, dietary, housekeeping, nurses, 12-hour shift...those faces change...

### **6.2.3 It's so noisy here**

Along with the busy pace of the hospital wards and the high turnover of staff caring for patients, the noise of the units could also be overwhelming. Sometimes the noise that I observed came from other patients. Overall, I noticed that on all of the units I spent time on that there were always several other patients, usually neighbours of the ALC patients I was spending time with, who seemed confused. Many of these patients would call out, often seeming to be in some kind of distress. At one point, Mrs. Ho was sharing a room with another patient who tended to call out frequently. Her daughter found this quite distressing and reported to me that her mother often seemed disturbed by the noise in her room. I experienced this myself during one early morning observation session, when Mrs. Ho's neighbor called out repeatedly for about twenty minutes.

Suddenly, her neighbor yells out. "Hahhhh!" he calls very loudly, over and over about three times....The neighbor continues to yell on and off for about four minutes, when a nurse comes in to say hello and check his blood sugars and do his morning vitals....All at once the neighbor begins his loud cry again. His voice is very loud, it is resonant and echoes in the room. This is surprising for a person who seems so frail. He sometimes punctuates his loud cries with more quiet moans. [FN: 11.06.2019]

On another occasion, this time in a four bed room where she had been moved to, there was a lot of commotion from two of Mrs. Ho's neighbours, who both seemed quite confused. One of the neighbours tended to yell "Help" over and over and talk out loud to herself, while the other neighbor seemed to be struggling with some pain issues and was moaning out loud off and on. During this particular afternoon, Mrs. Ho was sitting up in her Broda chair and watched, in some confusion, the following:

The care aide goes over to help the neighbor who has been talking to herself. The neighbor says to her “don’t try to kill me!” and the care aide quickly reassures her that this is not her intent. She is there to help her with her energy drink. The care aide says to me, “Everyone is confused in this room!” as another neighbor suddenly gets up from her bed and starts to walk around with her walker but in bare feet. Mrs. Ho watches the going on in the room, rubbing her hands together at times...[FN: 12.20.2019]

One of the family member participants [FM2] remarked on how the confusion and noise from other patients could be hard to deal with. Overall, she had found that her husband had quite a good care experience but as she explained,

The one bad thing I must say, this is the only...just one item I thought...but there’s nothing you can do about this either. There were two gentlemen that were in the room, not at the same time. But both of them were I don’t know, they were yelling and you know, I guess screaming and...And causing a commotion. And he didn’t get any sleep. So that’s when he got...he really got upset. He got discouraged.

In general, the overall and daily noise of the hospital unit could be quite intense. I observed the following, in terms of the cacophony of noise that surrounded Mrs. Wong during her morning care, while she was lying in bed trying to have a bowel movement after being given an enema.

“Swallow, swallow!...I hear. I think one of the neighbours is being given his crushed medications. “Swallow it”...”No! No! No! No!”.... “Swallow”.... “Beep! Beep” (a bed alarm)...quiet murmurs.... “Swallow it”....Rummaging noises outside the room.... “Help, help!” cries the neighbor... “Scratch, scratch” I hear as another patient moves his straw into his plastic drinking cup. I hear her husband say, “Big poo poo!”....The nurse says, “She’s basically given birth here!” (she’s had a large bowel movement) [FN: 10.29.2019]

These were some of the common challenges that patients had to deal with when it came to living day in and day out in a hospital, in terms of the noise, constant activity and changes that are characteristic of most hospital wards. As a result, it was difficult for patients and their family members to share living space, especially over a long period of time. The long-term sharing of

space seemed especially significant for the patient participants, as they did their best to dwell in and live their lives within the busy hospital setting.

#### **6.2.4 Sharing space**

There were not many private rooms in the hospital where I was conducting my research, and most of the participants I spent time with were sharing space with other patients, often in four-bed rooms. While this is common in many hospitals, the lack of private space takes on additional significance for patients who spend long periods of time waiting in this setting, as is the case with ALC patients living with dementia. Within the shared space that the patient participants inhabited while waiting, I observed many things happening around them on a daily basis that I suspected could be difficult to comprehend for those living with more advanced dementia. For instance, I observed intimate and deeply emotional events such as witnessing another patient's last days. While death and dying are also not uncommon in a hospital setting, I wondered what the patient participants thought of what they were witnessing when this was occurring? I observed the following while spending time with Mrs. Ho.

One of the nurses returns to the room to provide care to the very sick patient across the way from her. From where she is sitting it is apparent that Mrs. Ho can see what is happening by the bedside as the curtain is open a bit. She reacts with surprise at whatever she is seeing. This is apparent by the way she sits up a bit suddenly, and her mouth opens in surprise. [FN: 11.12.2019]

The patient across the way from her passed away the next day and I recorded variations of this observation while spending time with many of the participants, where sick patients were cared for and where some lived out their last days, often in pain and distress. The inhabitants within the shared spaces that the patient participants dwelled in were ever changing, with fellow patients dying or being discharged, different family members visiting, and so forth. In many cases,

particularly for the participants with very long stays, the ALC patients were the ones that remained the constant in these ever-changing shared spaces.

It was also difficult for established relationships to prosper or continue as they normally would within these shared spaces. Mrs. Rogers told me on one occasion that while “it’s been interesting” to be in hospital, that overall it was hard to be separated from her husband of many years, as they were not able to spend as much time together as she would have liked.

Meanwhile, Mrs. Wong and her husband carved out a small space within the hospital room where their relationship continued, surrounded by other patients, family members, staff and the daily routine of hospital life. He visited every day for many hours at a time, assisting with her care, talking to her, and reassuring her.

I hear her husband speaking quietly to Mrs. Wong. I happen to turn my head and without meaning to see that he is sitting facing her while she sits on the commode, their heads almost touching. This is hospital life, there are bodies voiding, excreting, basic life functions happening in a shared space where others are busy being washed and prepared for the day. [FN: 10.29.2019]

When I wrote this, I was struck by the intimacy of the moment I observed, which was sharply juxtaposed by the level of activity going on around them as other patients in the room received their morning care.

For Mr. and Mrs. Chiang, a married couple, it could be challenging for them to share space on the ward. Mr. Chiang had been hospitalized after a fall at home, while his wife did not join him in the hospital until about a month later. It was explained to me that Mrs. Chiang was admitted for compassionate reasons, as she was not managing at home without her husband who had been her primary caregiver prior to his hospitalization. They could often be found sitting together in the hallway by the nursing station, where Mr. Chiang was regularly placed in his Broda chair. They did not share a hospital room as staff had to keep them separated at times. One

of the ward nurses chatted with me one afternoon when I was sitting with the couple in the hallway, and I wrote the following field note.

The nurse comes to take Mr. Chiang's blood pressure and says that he can get agitated in the afternoon often when his wife is sitting by his side. The nurse explains that Mr. Chiang will sometimes ask Mrs. Chiang to remove his tray and will get upset with her when she cannot manage it. Staff will often have to separate them, especially in the afternoon when they start to sundown. The nurse also mentions that sometimes Mr. Chiang will get upset with his wife when she is not doing anything at all. [FN: 01.14.2020]

While Mr. and Mrs. Chiang could not always share the spaces they found themselves in without encountering some challenges, I did notice that on other occasions, they sat together companionably grasping each other's hands and conversing together.

I also observed that the different patients and family members in a shared room could form a special sense of community amongst themselves. For instance, in the room that Mrs. Wong and Mr. Lee shared, I regularly observed the family members of the different patients chatting with one another when they were visiting at the same time, which the patients also seemed to enjoy. There was gentle laughter, smiles, and a sense of cordiality and connectedness in their shared conversations and interactions.

The daughter is chatting with one of the neighbour's visitors as she feeds her father. They are speaking in their own language...The visitor of the neighbor and Mr. Lee's daughter continue to chat. The daughter looks up at me and says it is nice for them to talk together because they have similar backgrounds, referring to where they were born and the language they speak. They also have the fact that they are caregivers to older adults in common. Mr. Lee watches the ladies talk leaning forward at times, hands clasped together. [FN: 11.14.2019]

Despite the fact that the hospital was not really a home-like environment, I was constantly struck by the hospitality that patient participants and their families extended to me, almost as if I was visiting them in their homes. I had to be careful when I sat with Mrs. Chiang during meal times, as she would always try to share her meal with me, once going so far as using

her knife to separate the meal on her plate into two halves and offering me a fork to eat the portion that she set aside for me. Mrs. Ho would also try to share her meals with me, a kind offer that I would politely decline, and she would shake her head in disappointment. Whenever I came to spend time with Mr. Powell, he would always gesture to the chair by his bedside and welcomingly say “make yourself at home!”. Similarly, Mrs. Wong’s husband would insist on leaving the room and finding a chair for me to sit on when I would come to spend time with him and his wife, until I started bringing my own stool to sit on.

### **6.3 The In-Between Times**

Despite the fact that the hospital wards are busy places for ALC patients living with dementia, the patients themselves did not have much to occupy themselves with between periods of care. The busy-ness of each day, in terms of what the patients experienced, usually revolved around morning and evening care, meal times, and medication administration. These periods of times were unsurprisingly when the patients experienced the most hands-on care and interactions with nurses and care aides. I noticed that the periods between these regular interactions included long gaps of time where patients did not have much to do at all, or much contact with others unless family members or friends were visiting. This theme of The In-Between Times explores the long days the patient participants experienced, often sitting around with not very much to do.

#### **6.3.1 There is not much to do**

When I asked Mr. Powell about what normally happens during his evenings in hospital, he looked at me and said, “this is it”, shrugging his shoulders and motioning to his surroundings, where I noticed that not much was going on. He told me that prior to his hospitalization, he liked to stay busy and used to go out regularly, “...maybe to the club for a beer you know, or

something.” He was looking forward to moving to a care home so that he could have more to do. As he explained, “I think a care home sounds good because basically at a care home I might find some people I can work with or talk with. That’d be good.” Similarly, in one of our informal conversations, Mr. Hastings told me that he does a lot of “sitting and waiting”, which he found “a drag” at times. As one of the nurse participants [N5] explained, “...with patients living with dementia in an acute care hospital is difficult because sometimes we can’t do a lot of different programs to engage them so that is a challenge, so I feel that when they’re sitting there, they’re actually doing nothing...”

This sense of not having much to do was common for all of the participants, and long periods of each day were spent sitting by themselves, when there was no family visiting or care interactions with staff. As one of the nurse [N5] participants stated, “...there’s absolutely nothing for our patients who are ALC living with dementia sitting in the acute care hospital waiting for a bed.” One family member participant [FM6] described his father as bored and stated that “he is in limbo” as he waited for a care home. His father preferred to be busy and to be engaged in the world around him but did not have much to occupy himself with while in hospital waiting for a care home bed.

Several of the participants, particularly those living with more advanced dementia, kept themselves busy by folding and re-folding towels and blankets that had been given to them by staff or family members. Mrs. Wong liked to use towels to wipe her chair’s tray, or wipe her mattress down when she was lying in bed, as if she was cleaning it. Her husband told me that she has always been a very tidy person, and would often clean when she was at home. At other times, I noticed that she tended to pull at and fidget with her blankets. Her husband explained that this was because she “had nothing to do.” Mrs. Ho would engage in similar activities. I

watched her one morning carefully wipe her tray down, careful to shake out the cloth, proceeding to fold it up afterwards. Similarly, Mrs. Chiang would often spend long periods of time in her room, folding blankets, towels and items of clothing. I observed her in her room one morning, keeping herself occupied:

She has several towels on the bed and is carefully folding them...She has now accrued several cloth items on the bed: Gowns and flannels that she is sorting through. I see magazines and colouring supplies on her bedside table and there are a few sheets of colouring on her bed, pictures of teddy bears...She continues to carefully sort and fold various items. It looks like she has several sheets of paper towels that she is smoothing out. [FN: 01.15.2020]

In general, unit staff did not have much time to spend with patients, other than when it came to providing hands on care. Mr. and Mrs. Chiang were frequently given paper to colour on with pens and pencils. At times, they seemed to enjoy this activity, but this would only help to fill in short periods of time during the day. It also seemed more engaging for them if there was someone to participate in the colouring with them, as I witnessed a few times where there was an extra care aide available to provide 1:1 care and attention. One morning, when I was spending time with Mrs. Ho, I realized that staff had probably tried to give her something to do, in the form of paper and a crayon that she had tucked away inside her pajama top.

She gestures to herself, taping herself on her chest. I hear a crinkly noise and it appears she has a piece of paper down the front of her pajama top. I wonder, is this the menu from her breakfast tray from earlier in the day?...Suddenly I notice a blue crayon tucked under the edge of her pajama top. I reach over and pull it out, showing it to her. I ask her, "What's this?" She seems perplexed and takes the crayon from me...I suddenly realize that the staff probably gave her crayons and the paper currently in her pajama top as an activity, probably earlier in the day. I ask her about the paper again, she taps her chest and the paper under her shirt, after I gently and questioningly tap it. I ask her if I can remove the sheet of paper and she nods, allowing me to take it out. I pull out a sheet of paper that appears to have been neatly folded several times. She takes it and opens it up, sure enough I see a series of blue crayon marks. [FN: 11.4.2019]

After this happened, I started to think about how Mrs. Ho might have felt about being given crayons and paper, and whether she had found it odd to be offered such items of

distraction? While it could be that she enjoyed drawing, I felt a sense of discomfort at the time, as if she was being treated as a child who needed distracting. I somehow doubt that Mrs. Ho felt like drawing that morning when she was offered those items. I am not sure how I would have felt if I were an older person living with dementia, and a younger nurse plucked down a crayon and some paper for me? I also speculated about what it must be like to not have much to do, day after day, sitting in a chair in a hospital room. Overall, there was a sense of empty periods of time permeating the participants' days, and that I felt was illustrated in Mrs. Ho's case, who seated on her own in her room, tucked away drawing material in her clothing not having anything better to do with them.

### **6.3.2 I spend a lot of time sitting**

In fact, like Mrs. Ho, most of the patient participants spent time sitting alone in wheelchairs or Broda chairs, or sitting up in their hospital beds. Mr. Powell one day told me, "Sometimes I'll just sit in my chair out here for three, four hours." One of the nurse participants [N2] explained it well, when describing what it is like for ALC patients, in terms of not having much to do and spending a lot of time sitting around.

Because at that point when you're ALC, you know, your doctor isn't seeing you every day. You're not being seen by rehab because you're no longer needing it or you know, requiring it. I mean yeah, you get your nursing care. They come in and they feed you. They wash you, and then get you up in a chair and there you sit, right?

This was very much the case for Mr. Lee, who spent many hours in his Broda chair, positioned by the side of his bed, facing the bed opposite to his. When he was awake in his chair, he would often lean forward to peer past the curtain dividing his bed from his neighbour's so that he could see what was occurring in the hallway.

The daughter and her husband say goodbye, she waves at him and he waves back. He leans forward in his chair to watch them leave the room. Then, he sits back in his chair with his hands on his tray, part of his blanket is on the tray and he picks the edges up and

twists them a little. Every so often he leans over a bit to peer past his neighbour's bed, always watching what is going on around him, and what might be occurring in the hallway outside the room. [FN: 11.14.2019]

Later that afternoon, we sat companionably together by his bedside and watched what was happening around us.

I continue to sit by his side, every so often he will reach out with his hands and grasp mine, and then quickly let go. Most often he clasps his hands before him. He'll frequently lean over to watch other patients walking by with their walkers. We see cleaning staff pass by with their cleaning carts, the occupational therapist and the student working with her pass by the doorway at one point as well. At another point, a person comes to stock the incontinence pads on the shelf by the far wall. We watch all of this occurring together. During this time, he often stops to look at me and will smile. [FN: 11.14.2019]

At other times, I noticed that Mr. Lee's chair was placed further away from the edge of the curtain, so that he could not lean forward and look past it. In fact, it seemed that most of the time he spent in his chair was done while facing the closed curtain of the neighbor across the way from him. I often thought that he would have preferred sitting facing the room's door so that he could have more to look at, and felt that he was likely placed in this position because he had the tendency to vocalize quite loudly at times. Perhaps staff thought that if he did not have much to see or respond to, there would not be any stimuli to cause him to call out, which likely would be disruptive and require responding to. Overall, I thought it seemed a long and uninspiring way for him to spend each day, and I noticed that he would smile broadly and his face would light up whenever his daughters came to visit him.

I also noticed that patients were often positioned in their chairs in the hospital's hallways, usually close by the nursing stations. This seemed to be done for patients who tended to be more confused and agitated, where placing them by nursing stations meant that staff could keep an eye on them, and respond to any disturbances as needed. As previously mentioned, several of the patient participants in this study spent a fair amount of time sitting by nursing stations. At times,

some of the participants seemed to enjoy the busy-ness and level of activity outside of their patient rooms. It is likely that distraction from the boredom of their rooms was welcome. I spent some time sitting with Mrs. Rogers in the hallway by the nursing station one afternoon. She told me that she liked sitting outside of her room, and between short bouts of conversation with me, I watched her take in her surroundings with a smile on her face.

I came across Mrs. Ho sitting in her Broda chair by the nursing station on several occasions over the course of the time I spent with her. Her daughter told me that she enjoyed being out of her room, that she was an observant person by nature and that she liked to be a part of the world around her. As her daughter put it, her mother was so observant that she would sometimes report to her “how many coffees the nurses had had!” At the same time, her daughter told me that it was when her mother was not in a “good mood” that she would most often end up sitting by the nursing station. This seemed to refer to times when she would get upset with staff, or was banging on her Broda chair tray. It seemed a shame to me that she would only find herself outside of her room when she had been behaving in a way that warranted supervision, as it seemed that otherwise she would be left to sit on her own in her room.

In general, I was confronted with the dearth of activities to keep individuals occupied, particularly when I observed participants appearing quite bored, as they sat and waited around. For instance, on one afternoon, Mr. Hastings came to sit next to Mr. Chiang in the hallway by the nursing station, and I observed the following:

I see Mr. Hastings come to the door of his room again. He stands by the entrance and I hear him say, “Is there any way for me to get out of here?” He walks into the hallway and leans against the wall. He does not have his walker with him. Mr. Chiang is still reading his magazine. Mr. Hastings walks over to the nursing desk and stands there for a moment, then goes to sit in the chair next to Mr. Chiang. Mr. Chiang does not notice that Mr. Hastings has sat down next to him. Mr. Hastings runs his left arm along the base of the chair he is sitting on, as if he might be seeing something there. He leans forward for a bit in his chair then sits back in the chair with a sigh. He looks around for a bit, then leans

forward again and looks down at the floor. Mr. Chiang continues to read his magazine, he has not looked up for some time. Mr. Hastings leans forward in his chair and looks down at his lap, now leaning forward with his hands on his knees. [FN: 01.20.2020]

As I observed Mr. Hastings sit in the hallway, his ennui and weariness with sitting around were clear to see, as he ended up staring down at his feet for some time, before eventually heading back to his room



**Illustration 3: Sitting in the Hallway**

The ward that Mr. Hastings and Mr. Chiang were on did have a music therapist who would come for bi-weekly group and one-on-one sessions with patients. I once observed Mr. Chiang and Mr. Hastings in a group music therapy session and they both appeared to enjoy the music and the interaction. The music therapist also spent some one-on-one time with Mr. Hastings in his room one afternoon, and when I looked in on them, he seemed very engaged. Afterwards, mistaking me for the music therapist, he thanked me for the music, which he earlier had referred to as “a bit of sunshine”. While this unit did have some engaging activities such as music therapy, overall the

amount of sitting and not having much to do during periods of time between scheduled or regular activities was very noticeable on all of the wards. As I wrote in my field notes one afternoon, after spending some time sitting with Mr. and Mrs. Chiang in the hall:

We've been sitting her for almost two hours now. In terms of what we have been doing...we've not been doing much... I am stiff from sitting and I wonder if they are too?  
[FN: 01.12.2020]

## **6.4 While I Wait Things Can Change**

As discussed earlier in the Home..but not Home theme, there was much that changed around the patients while they waited to be discharged, in terms of staffing changes and the movement of other patients in and out of the spaces they shared. While this reflects the fluctuating and chaotic nature of the hospital environment, the theme While I Wait Things Can Change represents the changes that the patients experienced themselves. As a result of long periods of time spent in hospital waiting for alternate arrangements of care, many of the patient participants experienced substantial deteriorations and fluctuations in their health and wellbeing. Some of these changes were gradual and were experienced over time. In other cases, the patients had to confront sudden changes in their health status. In addition, while the wait to be discharged could be long, the suddenness of a bed becoming available in a care home could take patients by surprise. The following pages highlight the changes the patients experienced while designated ALC and waiting in hospital.

### **6.4.1 My health and abilities deteriorate**

As part of waiting in the hospital setting, in order to return home or be able to move to a care facility, the patient participants experienced significant changes in their overall health and functional abilities over time. Mrs. Ho was one of the participants whose health and abilities deteriorated. When I first met Mrs. Ho at the end of October, she required a one to two person

assist with transfers. By the time she moved to a care home in early January, she required a ceiling lift for transfers, as her strength and ability to transfer with assistance deteriorated significantly while in hospital. Certainly, her daughter noticed substantial changes over time, telling me that her mother became weaker over the course of her hospitalization. While there was some concern that she may have experienced mini-strokes during her stay in hospital, which could have accounted for some of her deteriorating condition, it was also clear that there were cumulative and detrimental effects of sitting for long periods of time, and of not being able to move around on her own. In addition, Mrs. Ho also began to have skin integrity issues towards the end of her hospitalization, where her bottom became red and excoriated. One of the nurses told me that this was because she was up sitting in her chair for most days, and her bottom had not been checked often enough. Towards the end of her stay in hospital, I noticed that she began to resemble Mrs. Wong, who spent nine months in hospital, particularly in how she was lying in bed. Mrs. Wong would often be restless when she was in bed, moving about quite a bit and fidgeting with her blankets. I recorded the following observation on the day before Mrs. Ho left for a care home.

Mrs. Ho is now talking to herself a little as she lies on the right side all scrunched up, her legs pulled up quite close to her chest. Again I feel that her movements are quite reminiscent of Mrs. Wong. She is fidgeting quite a bit, moving her legs around, scratching her head, scratching her left thigh, moving the pillows and blankets around.  
[FN: 01.08.2020]

It is important to acknowledge that Mrs. Wong and Mrs. Ho were unique individuals, and my intention is not to depersonalize them by comparing them and likening one to the other. Rather, I realized at this point, towards the end of Mrs. Ho's long and difficult hospitalization, that her overall physical condition had deteriorated significantly, and that her body movements were

similar to Mrs. Wong's, who had been in hospital for many months and whose physical functioning had likely worsened as a result of this.

Mr. Lee was one of the patient participants who ended up going back home with his daughter, with home supports in place. I was able to visit Mr. Lee and his daughter at home about a month after he left hospital and his daughter reflected on the physical changes and decline that she noticed in her father over the course of his hospitalization. Mr. Lee was dealing with body contractures now that he was home, and his daughter was providing stretching exercises under the direction of the community physiotherapist. While I was visiting them at home, the daughter told me that prior to his hospitalization he used to be able to manage the stairs to get to his bedroom upstairs. There was now a hospital bed set up in the living room, with an overhead lift installed. I had not realized how much things had changed for him physically while he was hospitalized. Mrs. Lee's daughter explained that shortly after he was admitted to hospital, the rehab team tried to help him walk and that he refused and seemed unable to. She wishes that she was present during that time and wondered if she might have been able to encourage him to walk. She thinks that he was disoriented and unsure where he was, and that was why he would not attempt to mobilize. According to her, he was not mobilized again after this attempt. While I realize that it is likely that his physical abilities had been in part affected by the fall that brought him into hospital, it was also clear that spending all of his time in either his bed or Broda chair further contributed to his immobility and decreased functional status.

One of the family member participants [F5] discussed a similar experience, where she noticed that her father became less able to walk over time during his hospitalization. As she explained, "So when we would come and walk with him, that was okay but we started to notice that he wasn't able to go as far as he used to." Eventually her father was not able to mobilize

much at all, which meant that he spent more time sitting in his wheelchair, which then led to other problems. She stated, “He was...so now he’s not walking. He’s de-conditioning so they would keep him in the wheelchair. He started doing things like stripping.” As she explained, when her father started to disrobe, this would agitate other patients, so staff started to keep him in his room, which further contributed to his overall decline. As one staff nurse said to me one day during an observation session “You don’t use it, you lose it!” referring to the tendency for older patients not mobilizing enough to lose their abilities over time. One of the nurse participants [N2] also referred to the problems that can arise when patients are not able to mobilize enough. As she stated, “They’re not able to walk a lot and I think the nursing staff here, they’re trying their very best to walk their patients. But still the time is probably like once or twice a day so in terms of their mobility functioning, it’s kind of like not really helping them to maintain their functioning level.”

I witnessed Mr. Chiang’s abilities and overall wellbeing deteriorate over the time that I spent with him. His wife was discharged before him, and although staff felt that he might act out less without her around, it was my impression that he could get frustrated more easily without her regular presence. There was a period of time after she left, where he seemed to struggle quite a bit with calling out, especially when he was seated in his Broda chair. During that time, I heard more frequent reports from staff that he had been calling out and aggressive at nighttime, and that security had to be called several times to help calm him down. While I discuss the patients’ distress more specifically in the next chapter, what I want to draw the reader’s attention to at this point is the decline I noticed in Mr. Chiang’s mobility and his ability to engage with those around him at this stage of his hospitalization. After his wife’s discharge, he started sleeping a lot, and was often quite drowsy. I suspected this was because he was receiving medications to

help calm him down. For instance, I came to spend time with him one afternoon and he looked at me with blurry eyes, and did not smile as he often would. I recorded the following in my field notes:

He spends some time fidgeting with the zipper on his down vest that he is wearing over his PJs. He examines the zipper for several minutes. He then simply stares down at his magazine until he falls asleep. The clinical educator mentions to me that he has been quite drowsy. [FN: 01.30.2020]

This was early in the afternoon, and he was still sleeping deeply when I left the unit more than an hour later. The next day, I happened to be present when an aide helped him out of his Broda chair so that he could go to the toilet. I noticed that he seemed to have some trouble getting out of his chair, and that his steps were mincing and slow as he walked down the hall. The aide told me later that she had noticed that he was not mobilizing as easily as he usually did, and also reported to me that Mr. Chiang's son had told her he had noticed the same. Around this time Mr. Chiang also started to not eat as well as he normally did. He usually had a robust appetite, and accordingly the nutritionist had ordered double portions for him and I regularly observed him eating all of his food. However, I noticed that he started to leave food uneaten and was refusing his snacks. In addition, he started to experience lower extremity swelling, likely from sitting so much and not mobilizing, and TED<sup>5</sup> stockings were ordered to help with the edema. Over a period of ten days, I watched his health decline and I began to worry that his deterioration would continue to get worse as time went on. I wondered if I would come on the unit one day to find that he now needed a ceiling lift to transfer, or worse.

Fortunately, the nurses involved in his care adjusted his care plan soon after this, and they started to allow him time to sit in a wheelchair without any restraints, rather than restrain him in

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<sup>5</sup> A type of compression stocking

the Broda chair. This was not always successful, as there were periods where he would wander excessively and staff would have him sit in his Broda chair again. However, there began to be longer periods of time where he could sit without any restraints, as well as times when he could get up and walk around a bit on his own. After this change in his care plan, he started to improve and was soon mobilizing quite well again. This was a positive turn of events, but Mr. Chiang's period of decline illustrates clearly the perils of immobility and over-sedation, and how quickly patients' abilities can deteriorate.

#### **6.4.2 Suddenly it's time to go**

While it seemed that the wait for a care home could be interminable, and that not much was happening during this time, substantial changes in circumstances or in plans could occur, sometimes suddenly. For instance, Mr. Powell's plans to move to a care home changed quite unexpectedly on the planned day of his departure. Initially, he and his wife had received good news that a bed had become available in his care home of choice. Often when a care home bed comes available, there is not always a lot of warning for patients and their families, sometimes as little as 24 hours warning in advance. This had been the case for Mr. Powell and his wife, for at the time he was told that the bed was available he was also informed that he would be leaving hospital the following day. While this was a sudden change, this was a welcome one as he was quite pleased and looking forward to leaving the hospital. Unfortunately, Mr. Powell's transfer to the facility had to be put on hold and eventually cancelled when it was discovered on the morning that he was supposed to go, that he had an infection that required him to be placed in isolation. He had to remain in isolation for almost two weeks and as a result of this, lost his spot at the care facility.

Fortunately, less than two weeks after coming out of isolation, Mr. Powell was offered a bed at the same facility and to both his and his wife's relief, was able to transfer to it without any further setbacks. On the day that he was finally able to leave, I went to spend some time with him. On the morning of his departure, his wife came in to be present when transport came to pick him up. She was relieved and happy that he was moving to the care home, but alluded to not wanting to take the move for granted until it happened for sure.

When I come into the room, Mr. Powell is lying flat on his back. I notice that all of his possessions are packed up in the ubiquitous white patient plastic bags, lying by his bedside. I ask him how he is doing, and he says he feels good. He is smiling but seems a little subdued this morning. He tells me that he is washed up and ready to go....Soon afterwards his wife comes in, she seems to be in a very good mood. She brought with her a few bags with some of his possessions from home. As she came in, Mr. Powell asked her what was new? She joked saying that she has not really told anybody about the move happening this morning, just in case something happens to prevent the move like last time. [FN: 11.21.2019]

It was never clear how Mr. Powell acquired his infection, but his experience illustrates the precarious nature of being a hospital patient, particularly one who has been hospitalized for a long period of time, and how quickly one's situation can change.

Mrs. Rogers move to a care facility happened very quickly as well, again with only 24 hours' notice. I spent the morning with her on the day of her departure, and she told me that the suddenness of the move was anxiety provoking.

We talk about the fact that she is leaving today. She says to me, "I can't believe how quickly this happens," referring to the suddenness of her upcoming discharge. I ask her what she thinks about all this and she says to me, "I can't talk right now," explaining how difficult it is to take in and talk about the suddenness of this upcoming change. I ask her if I should go? And she says to me, "no, you're a good support right now." I ask her if she knows where she is going, and she says she's not sure. I take out my phone and show her a picture of the facility on the Internet. She says to me that it looks nice. I also show her where the facility is on the map of the city...She waves to the other ALC patient in the room. Again she reiterates, "It happens so quickly!" I ask if she can describe how she's feeling right now? She says to me, "I feel harried"... [FN: 11.21.2019]

While we were waiting for the transport team to come and pick her up, I offered to use my phone to call her husband. She was able to chat with him for a few minutes, and this seemed to help with her uncertainty and anxiety in term of what would be happening that day. While we were sitting together afterwards, one of the care aides who had gotten to know Mrs. Rogers quite well during her stay in hospital came in the room and reflected on the challenges of transitioning to a care home:

I tell her that we have just phoned her husband because she is feeling anxious. The care aide nods in understanding. She says "new environment, and new bed, new pillows, new approach..." in consideration of the changes that come with moving to a new home and that are awaiting Mrs. Rogers. [FN: 11.21.2019]

I also spent time with Mrs. Ho and Mr. Hastings on the day of their departures. Most of the patients moving to facility required a stretcher for the move. There is a dedicated service in the region that provides transportation for patients, usually between hospital sites, and for when they are discharged home or to care facilities. Mr. Hastings was able to leave the hospital in a wheelchair, but Mrs. Ho, like most of the other patients was transferred from her hospital bed directly to a stretcher. I recorded the following field notes as she left on the day of her discharge, describing her last few minutes in hospital:

As they wheel her out of the room, I approach her. She utters a cry of surprise when she sees me, smiles and reaches out her hands. I grasp them and say goodbye. She smiles at me. They wheel her away and I glance over at her unoccupied hospital bed, sheets stripped, a light flashing at the foot of the bed from the bed alarm going off when they initially moved her. Just like that, she is gone and is going to her new home. [FN: 01.09.2020]

## **6.5 Chapter Summary**

After spending many hours over several weeks with the patient participants, it was always a bit wrenching to say goodbye, or to come by their hospital rooms only to find an empty bed or new patient already installed there. However, it was good to know that they were now

moving on to a more permanent setting, for as it has been described in this chapter, their hospitalizations had been characterized by long stays in a busy environment, where they experienced many changes around them and within themselves. Unfortunately, the challenges that accompanied their long stays in hospital came with a fair amount of distress and upset for the patients. This particular aspect of their hospital experiences is depicted and explored in the following chapter.

## Interlude IV

### Hospital Sleeping<sup>6</sup>

He stares down at his magazine  
...until he falls asleep  
He does not rouse...  
despite activity going on around him

He is reclined in his Broda chair  
...his knit cap on  
His legs rest on a pillow...  
he is deeply asleep

He has been sleeping non-stop  
...has not moved  
He suddenly coughs, moves his head a bit...  
but does not open his eyes

He is almost like a person  
...having a nap in an armchair  
At home...

But not....

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<sup>6</sup> Written with excerpts from Field Notes for Mr. Chiang 01.14.2020-02.18.2020

## Chapter 7:

### In Sharp Focus - Distress and Behaviours

*I think it must be very frustrating and terrifying for them from what I see, right?(Mr. Hastings)*

#### 7.1 Overview

Overall, it was not uncommon to observe patients becoming upset at different points throughout their days in hospital, and there seemed to be a variety of reasons and causes for their distress. Personal care was often a trigger for many of the patient participants I spent time with, particularly peri-care. Invasive procedures like catheter insertions could also be quite traumatic, and sometimes simple and routine procedures such as the taking of vitals could be challenging. Restraining patients in Broda chairs and with the use of medications was also common. As a practicing nurse I have witnessed and had to deal with “behaviours” in my career. However, for this research I was focusing on the patients’ experiences and perspectives as an observer and a researcher, and the raw and intense distress that emanated in their vocalizations, and that was evident in their facial expressions and bodily movements, shocked me at times. It was clear to me that I was witnessing verbal and physical expressions of fear, anger and confusion.

While I had understood in the past that these emotions were likely reasons for “behaviours”, I had always filtered these understanding through a clinical lens. Moving away from a clinical standpoint was important when focusing on the patients’ distress, as this work was about their perspectives and reactions, and not about trying to understand clinical or medical causes for why they might be upset. In this sense, the themes presented in this chapter revolve around the visceral feelings that participants expressed and the reactions that I observed when they were upset. This perspective also centers on the labeling and “othering” they encountered

by the people around them, and the consequences they confronted when they acted certain way. As such, the following threads are explored in this chapter: Am I Not Behaving Well?, I Am Defined by a Sign, and Why Am I Restrained?

## **7.2 Am I Not Behaving Well?**

Overall, patients who regularly experienced distress, and manifested it in some way whether by yelling or calling out, or in a physical manner such as by hitting or kicking at care providers, were labeled as having behaviours. When behaviours were challenging, such as when patients hit out at nurses or yelled a lot, providing care could be extremely trying for staff. When patients had particularly bad days, I heard nurses refer to them as being “naughty”, “difficult” and “terrible”. I often heard nurses talk about not wanting to get hurt by a patient who was acting out. Certainly, if patients were found to be difficult, or aggressive, it directly affected nurses and other caregivers, potentially putting them at risk of physical harm. As a nurse myself, I could empathize with the fear of getting injured during care, and was not surprised to hear nurses and other staff say things such as “don’t bite me”, “don’t hit me” and “I’m afraid to get hurt”.

### **7.2.1 What’s the problem here?**

As mentioned above, from a clinical perspective, I had found that the focus as a nurse had been to identify triggers for responsive behaviours, and to rule out other causes such as infection that could be contributing to a patient’s acting a certain way. Certainly, whenever patients exhibited behaviours that were problematic, it was common for staff to search for a reason or cause for the behaviours. For instance, Mr. Chiang’s behaviours were very challenging for staff, and at times, the nurses would ask his doctors to assess him for infections, or other physical reasons that could be causing his distress. I recorded the following during one observation

session when the unit team was following up with the physician in regards to Mr. Chiang's behaviours:

Earlier, the PCC and an internal medicine physician were discussing Mr. Chiang at the nursing desk in front of where we are all sitting. They are discussing whether there might be other reasons for his agitation, such as a medical reason. It is mentioned that Mr. Chiang has been assessed by Geri psych and he is now being trialed on a new medication but he is still getting quite agitated at times. The PCC refers to this morning's episode when Mr. Chiang "was terrible ". I hear that Mr. Chiang is now on Risperidone and they mention that Mrs. Chiang will be going home tomorrow and that this will be a good thing as Mr. Chiang gets frustrated with his wife. She is a trigger for some of his agitation, but why this is so is not clear to me. [FN: 01.16.2020]

I was sitting with Mr. Chiang one morning when the hospitalist came to assess him, after several days of problematic behaviours where he had been calling out a lot during the night. Mr. Chiang was in his bed, sleeping deeply after being up for most of the night, and after receiving medication to help calm him.

The hospitalist comes in and quickly examines Mr. Chiang. He listens to his lungs, checks his feet and presses on his abdomen. Mr. Chiang rouses slightly and mumbles a few replies but falls asleep immediately afterwards. I mention (to the doctor) how sleepy Mr. Chiang has been. "If you have any science you could share that would help," the doctor invites to me. [FN: 01.28.2020]

The hospitalist was aware that I was a researcher, and I was not sure how to answer him about whether I had any "science" to share with him in terms of what could help Mr. Chiang with his behaviours. At the time, I felt like telling the doctor that Mr. Chiang was simply not happy in hospital, and that the problem was likely that he was stuck in his chair most of the time.

However, I refrained from these comments as I did not feel that this would be helpful. Following his quick examination, the doctor did order a decrease in Mr. Chiang's sedation.

### **7.2.2 Consequences and impacts of behaviours**

As mentioned previously, patients who were noisy, calling out or behaving in ways that were hard to control, often found themselves sitting in the hallways. Other times, staff would

leave them to cool off on their own, if they had been “uncooperative” or “difficult” during care.

For instance, I observed Mrs. Ho receive her morning care during one of her last days in hospital, which she found difficult as was often the case for her.

Two nurses come by to change her and get her up. I can hear her making the odd yelping sound as they provide care. « It’s OK!... You’re OK Po Po<sup>7</sup>!” I hear them say to her. I can hear her talking to herself or to the staff providing care, at times she says “Hai” as if in affirmation, but then will yelp quite loudly. “Shhh Po Po” I hear a nurse say from behind the curtain. I can hear her panting a bit as care is provided. “Oh yeah, it’s really red!” I hear one of the nurses say and I think they may be talking about her skin integrity, possibly the skin of her bottom. Periodically she yelps loudly, and intersperses this with panting, then talking out loud. [FN: 01.08.2020]

Following the care, during which I sat behind the bed’s curtain, the two nurses who had been helping her to wash left her bedside without saying anything to her. They left the curtains drawn and her untouched breakfast tray by her bedside. I was unsure why they did not set her up for breakfast before they left. About twenty minutes later, when one of the nurses came back, I asked if there was a reason she could not eat, wondering perhaps if they were delaying her meal because she had to go for a medical test. I was told that she could eat but that “she didn’t look happy” after care and that they did not think she wanted to eat. I thought to myself afterwards that perhaps she might not have wanted to eat right after care, but this was hard to know.

However, what struck me the most was that she was not really given a choice when the nurses left her in bed and decided on her behalf that she was not up to eating because she was in a bad mood. After the nurse left, I offered Mrs. Ho some of her breakfast, which she ate eagerly.

How a patient behaved also seemed to have direct implications on their chances of finding a care home. The more behaviours that a patient exhibited, particularly aggressive and potentially dangerous ones, the less likely a care home would want to accept them if a spot

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<sup>7</sup> A Chinese term for grandmother

became available. I was told by one of the social workers that people who do not have as many complex needs can get “placed” more easily. As one of the nurse participants [N2] explained to me when discussing ALC patients,

I mean technically, the care of them should be simpler because they’re medically stable; however, when you throw the dementia into it, it makes it a little more complex because if they have behaviours, right? So say if they’re climbing out of bed or they’re aggressive or resistive to care, then we have to try and I’m going to say “fix it” with quotations because you can’t really fix dementia but in order to get people to placements, a lot of care facilities are picking and choosing their patients so if somebody is...has behaviours or resistive to care, they’ll say no.

I was told that challenging behaviours accounted for some of the long stays that participants experienced, and I considered the effect of prolonged hospitalization for these patients, and the potential that this had on exacerbating, or even causing behaviours. One of the nurses [N4] reflected on this same idea when talking about one of the ALC patients on her unit who had been waiting a long time. As she stated, ‘maybe he wouldn’t need special care if he [hadn’t] been hospitalized for so long.’”

### **7.2.3 Don’t touch me.**

For many of the participants, particularly for those living with advanced dementia, personal care could be frightening and unwanted, even when needed such as after a bowel movement. I frequently was present during personal care, sitting behind the bed’s curtain to respect the participant’s privacy, and witnessed how distressing the experience of receiving personal care could be.

The nurse comes in with a basin filled with water. She closes the curtain and the husband stands on the right side of the bed. They remove Mrs. Wong’s gown and start to wipe her down. Mrs. Wong’s voice rises and she speaks quickly. The nurse and the husband reassure her. I hear the nurse say, “I know, I know, I know you don’t like it”. Another nurse comes in to help as they change her pad. Mrs. Wong sounds really upset. “Aiiiyah!” she calls out, and her voice rises... I hear her husband’s voice rise for an instant and she stops calling out. He continues to reassure her. I can hear them changing her pajamas. One of the nurse says, “The wrestling match is finished” now that the

personal care is done. “On to the next match!” I hear. “It’s a wrestling match,” the nurse says to me as she walks by. [FN: 11.15.2019]

This was a common experience for Mrs. Wong, whose husband told me that she does not like to be touched by others. He was almost always present during personal care interactions, standing by her side reassuring her, as well as physically helping the nurses out as needed. He explained to me that if he was not there to reassure her and help out, that she could become very agitated, and as he explained, she could “lose control”. Ensuring that he was present whenever he could be, in order to help manage her reactions to care, took its toll on him.

It seems that he feels that he needs to be present most of the time, as much as possible to keep her calm. He explained that she doesn’t sleep as well when he’s not there. I stated something along the lines that this must be hard for him. He seemed to be struggling with emotion, looked at her then looked at me and said, “I feel it is my duty.” [FN: 10.29.2019]

Similarly, Mrs. Ho’s daughter explained to me that her mother did not like to be touched by others, and that she had always been very private when it came to her body and having other people assist her with personal care. Overall, I observed that she could become very upset during any type of personal care, calling out and frequently striking out at her care providers.

The nurse returns with another nurse. They draw the curtain and tell Mrs. Ho that they will reposition her and change her pad. They start to lift the bed and remove her covers. I can see the bottom of the bed but not Mrs. Ho. I hear her utter a sound of distress, slightly high-pitched, it is the only sound I have heard her say today. I hear one of the nurses say “don’t hit, don’t hit!”...They complete her care. I hear one nurse comment on the expression in her eyes. I think she must not be happy....They tell her that she will be getting up but as they position the chair and lower the bed, reaching over to try to help her out, she kicks one of her legs at the closest nurse. The curtain is now pulled back and I see that her eyes are focused, glaring at the nurses, her chin is furrowed and mouth is pinched. The nurse reaches out her hand and says, “Don’t kick.” Mrs. Ho then reaches out and shakes one finger at the nurse and shakes her head. She does not make a sound but it is clear that she does not want to get out of bed. [FN: 10.31.2019]

Following this care interaction, the nurses decided to not get her out of bed, shrugging their shoulders and telling me that they tried. Similarly, on another occasion, I observed the following:

The care aide says, “dirty, dirty” quietly. Mrs. Ho cries out one time. “Shh, shh,” I hear the nurse say. I hear the sounds of care being provided and then one of the staff members says, “Mama, you’re going to turn to me.” I hear Mrs. Ho grunting, she cries out again. “Shh, shh, it’s OK,” I hear someone say. Mrs. Ho starts to call out quite loudly. She is being cleaned with wipes, they look like baby wipes, and I can tell that a cream is being applied. The care aide gently says, “Mama, change, change,” but otherwise there’s not much dialogue going on. Following what I surmise is the changing of her pad they reposition her. She cries out again, it is a guttural cry and then I hear her pant slightly. I hear someone say, “no hitting!”. [FN: 11.03.2019]

It was hard to know whether Mrs. Ho’s distress originated from her discomfort with having others touch her body, or whether it was because she was confused and unsure what was going on. It was likely a combination of these factors and as time went on, it became clear to me that most types of physical contact, such as personal care and transfers, could upset her. At one point, Mrs. Ho had to go for an X-ray to investigate some shoulder pain. While her daughter accompanied her to the procedure, she was not allowed into the X-ray room to assist and reassure her mother. As the daughter told me afterwards, “They thought they could handle her”, but Mrs. Ho became quite distressed and screamed throughout the procedure according to her daughter.

Mrs. Ho also required a permanent indwelling Foley catheter, despite attempts to trial her without one over the course of her hospitalization. According to her daughter, she needed the catheter because she could not void on her own. She found the catheter uncomfortable and often would try to pull it out. Unfortunately, new catheters had to be inserted several times while she was in hospital and these care interactions by all accounts tended to be quite traumatic for her, sometimes requiring soft wrist restraints and up to four nurses to help out and hold her down during the procedure. I was never present during one of the catheter insertions but was told by

one of the unit's nurses that they could be very difficult for staff, and especially for Mrs. Ho. She often had blood-tinged urine in her catheter bag in the days following a re-insertion.

When I arrive at the bedside, the daughter is there. Mrs. Ho is curled up on her left side, asleep. The daughter points out the catheter bag, it is half-full of very dark red urine. She tells me that they trialed her without a catheter yesterday but that she didn't void on her own. They had to put the catheter back in today and the daughter thinks it did not go well, that she fought quite a bit. Lunch arrives and the daughter tries to wake Mrs. Ho up, to no avail. "She's exhausted..." the daughter says referring to the experience this morning with the catheter insertion. [FN: 11.18.2019]

Hearing participants verbalize and call out during personal care was common during my observation sessions with other participants as well. For instance, Mr. Lee was mostly non-verbal and often would yell quite loudly during personal care. His utterances were usually quite guttural, and could easily be heard outside of his room.

A care aide comes in to say hello and tells me that she will be washing him and getting him up. She prepares a basin with warm water and soap, and closes the bedside curtains. She speaks to Mr. Lee in his language. I hear her wringing out a cloth in water and I think she has started to wash him. He vocalizes, one drawn out cry, "Aaohhhh!" and the care aide reassuringly talks to him as she continues to provide personal care. He does not utter another sound for a few minutes as she continues to speak to him. Then, "Hiiiyaaaa," he calls out twice, quite loudly...I hear the sound of the bed being re-adjusted, as well as the sound of water being wrung out again, and the sound of a towel wiping skin. Overall he seems to be tolerating his wash well. "Haiiiii!" he calls out loudly again. Another aide comes in and pops her head behind the curtain. "I didn't know you were here," I hear her say, "I was going to help you." "I saw that you were busy and started." Explains the first care aide, also stating that she knew the other care aide would hear Mr. Lee call out and would then come and help. [FN: 12.23.2019]

I was struck by fact that the first care aide started care knowing that Mr. Lee would call out, and that his yelling would effectively notify other staff that it was time to come help. I do not think that the care aide was trying to purposely be callous. Rather, it was clear to me that staff knew that personal care was a trigger for Mr. Lee, and that a certain behaviour, in his case loud vocalizations, was expected. After this interaction, I became aware of how normal it was to have

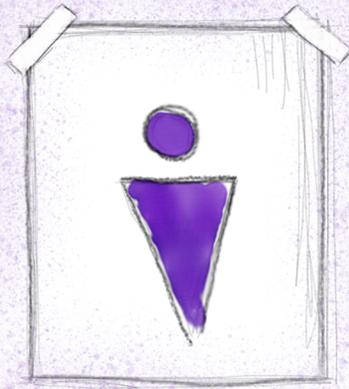
patients calling out during personal care, and how nurses and other staff simply expected and accepted that this could happen. More importantly, I realized that while having patients call out and get upset during care was both a routine and acceptable occurrence for staff, each experience was extremely distressing for these patients.

### **7.3 I am Defined by a Sign**

Patients who regularly exhibit aggressive behaviours in our health care system are identified by a sign, that is usually placed by their bedside or on the door to their rooms, as a way to warn and protect others who might come into contact with them when they are upset and “acting out”. The sign is basically a purple symbol that resembles an upside-down exclamation mark that is triangular in shape. Six of the eight patients that I spent time with were identified as aggressive and had the “purple sign” by their beds. I asked one of the nurse participants to describe the purpose of the sign to me, and she stated the following:

So purple sign is a flag for the potential for violence. We need to do that if they had an incidence of violence. That is the flag to make sure that we know that they have the propensity if their care needs are not met, okay? So it is a requirement by Work Safe BC to flag because very often we have staff that is not knowing that the patient has propensity for violence, that they are hit by the patient. So as an organization, they had to come up with a system where we can identify that the patient is purple...with a V. That allow us to understand and usually with V we try to make sure if there are care needs to be met, that there is a care plan. And sometimes you have patients living with dementia with behavioural, psychological symptoms of dementia - BPSD. No amount of drugs can decrease the incidence of violent behaviour from them and the last thing we want to do is just because they have that is that we sedate them forever. [N5]

While this description provides a solid rationale for the sign’s use, this theme explores the deeply stigmatizing and labeling nature of these types of safety procedures.



**Illustration 4: The Purple Sign**

### **7.3.1 Am I a troublemaker?**

Mr. Hastings, who had one such sign hanging by his bed, seemed well aware of the implications of this signage, despite living with a significant and chronic delirium which at times made it difficult to understand what he was talking about. On the day of his discharge to a care home, I observed an interaction between him and the unit social worker, where the social worker answered his questions about why he needed to go to facility. During their discussion, he suddenly refers to the sign.

Mr. Hastings also starts to talk about the sign on the wall that pertains to him. As he explains, “It has a blob on it, and a triangle...it looks like a woman,” and he says that it labels him as “a trouble maker”. I wonder if he is referring to the purple aggression sign? He then talks about inter-island postal and boat service and has asked her about his transfer to the new care home – is it also an inter-island transfer? She says that she is not sure what he means... [FN: 01.28.2020]

Later, after the social worker had left, I asked him about what he was referring to in his conversation with the social worker, and he was able to share his feelings about the “purple sign”.

I ask him about the sign with blob and the triangle that he referred to earlier. “Is that the one?” I ask, pointing at the purple sign hanging over his bed. “Yes,” he says looking at it, “trouble maker...” he repeats, shaking his head. “It is unfair,” he explains. [FN: 01.28.2020]

I overheard a nurse refer to her patients as troublemakers one morning. I am not sure if she was referring specifically to patients with the purple sign or not, but the implications in her words that certain patients are more trouble than others was clear.

The nurse comes in and Mrs. Rogers looks at her and says to me, “she’s the grumpy one.” Another nurse comes in and says to Mrs. Rogers’ nurse, “Are they being troublemakers?” I wonder if she is referring to the patients in the room? The primary nurse says, “They all are.” [FN: 11.21.2019]

The signs were clear reminders of the possibility of aggression, outbursts and sometimes violence. Mrs. Ho’s daughter told me that her mother, who had a sign by her bed, once bit one of the nurses. On another occasion, a care aide came by to warn me about Mr. Lee, while I was sitting with him, telling me that he could be “unpredictable” and that “he can grab, pull and sometimes hit people.” For some of the participants, their outbursts could lead to staff calling a Code White, where security guards are called to help calm an aggressive patient. I never witnessed a Code White during my observation sessions but one that was called because of Mr. Chiang, was later described to me by a staff member.

I am told that around 1:15 AM he wanted to get up to go to the bathroom. When he was helped out of his chair, rather than go to the bathroom he went to the nursing station and started rifling through papers there. He struck out at the care aide when she tried to redirect him but did not make contact as she was able to avoid him. They had to call security to get him back to his chair. Three security guards supposedly came and he was medicated. I asked if he was yelling when this happened and the care aide said yes. Not

his usual calling out when he calls “Hallo!” but more inarticulate yelling. I am told that he was settled in his chair but this only lasted about an hour when he started calling out again and security had to be called once more. [FN: 01.27.2020]

My understanding was that security could physically restrain a person if necessary, but in Mr. Chiang’s case, I was told that he recognized the authority of the security guards’ uniforms and would quickly calm down whenever they were called to the unit. I was also informed that security in the past had also been called for his wife Mrs. Chiang, who had to escort her back to room at one point.

### **7.3.2 The stigma and the shame**

Family members were also well aware of the signs hanging by patients’ beds. For some, it was hard for them to accept that their family members were labeled as aggressive. I had the following interaction with one of Mr. Lee’s daughter one afternoon that illustrated this:

I notice that his aggression sign is prominent at the head of the bed. His daughter says he does yell at times but that is his way of expressing himself. She has been told that he will sometimes hit out at the nurses...she says she doesn’t know why? She also says that he doesn’t do that at home. [FN: 11.14.2019]

As time went on, Mr. Lee’s reactions with nurses became more problematic, much to the dismay of his family.

His daughter perches on the side of the bed and recounts to me how a doctor approached her sister the other day to tell her that her father had been aggressive with staff, hitting the nurses during care she tells me. She says she is “perturbed” by this, pointing to the purple sign above her father’s bed and explaining that she thinks the staff should be prepared to deal compassionately with people living with dementia, who can “lose control” easily. I ask her when her father’s aggression mostly occurs, and it seems from what she says that personal care can be problematic, especially when her father’s blood pressure is taken. The daughter explains to me that the doctor approached the family to check if they were okay with the health care team no longer checking his vitals daily. [FN: 12.20.2019]

As we continued to talk together while sitting with her father, she explained that she did not think that regular blood pressure checks were necessary for him, as he did not have any health concerns other than dementia, and was not on any antihypertensive medications. She also reflected on the high amount of patients living with some type of confusion on the unit, and in her father's room, commenting that it seemed nurses should be prepared to deal with confused patients. She worried that her father was being stigmatized because of his dementia and confusion.

We discuss how she and her family feel about what the doctor reported to them in terms of her father's aggression. She says that she does not want her father discriminated against, referring to his dementia diagnosis. She looks at him, sitting quietly in his chair, smiling at her and she wonders aloud, "Does he look aggressive to you?" [FN: 12.20.2019]

While on the most part I saw nurses and other staff members provide care to the participants with respect and kindness, I could also sense the exasperation and frustration that staff often felt when caring for patients who were agitated and aggressive. Unfortunately, family members could be made to feel badly about patients' behaviours, as if either they or the patient were to blame. As one family member described,

Well, I feel bad as a family member knowing what that means right? In the hospital, you were made to feel bad too. The surgeon told me you know, "He kicked a nurse. We can't have that. Your Dad can't behave that way." And I'm like, "What? Like I agree with you. I'm not going to disagree but he's combative for a reason. He doesn't know where he is and what's happening to him." But I was shocked by that. [F5]

It should also be mentioned that the "purple sign" could follow patients to different care settings, for example when they moved on to a care facility. While information about a patient's propensity to act out in ways that could put caregivers at risk is an important detail to pass on,

there is always the risk that a person could continue to be labeled as aggressive or violent even when the circumstances that might have contributed to the behaviour have changed. Reflecting back on Mr. Hastings reaction to the “purple sign” over his bed and his understanding that it labeled him as a troublemaker, it was clear that he was uncomfortable and displeased with this characterization. His son explained to me that earlier on, when Mr. Hastings was first hospitalized prior to being repatriated to the hospital where I got to know him, he had been quite agitated and confused. His son found that overall he was much calmer now. Nevertheless, the warning that he could be potentially aggressive continued.

#### **7.4 Why am I Restrained?**

In addition, when patients exhibited behaviours that staff found difficult to manage, it was not uncommon for patients to find themselves restrained in some manner. This could take the form of physical restraints, such as soft wrist restraints or trays on Broda chairs that kept people seated in place. Chemical restraints in the form of sedating medications were also used. Over the course of several observation sessions, I witnessed the effects that restraints had on the patients I was spending time with. This theme is explored and described in the different ways that the patient participants found themselves unable to move their bodies freely, whether held in place physically by their chairs or by other people, or by being sedated by medication.

##### **7.4.1 I can't move about freely**

Many of the patient participants in this study used Broda chairs. In some cases, the chairs provided support for those with substantial physical challenges, but for others, the chair served as a method of keeping people in place, especially if a patient was prone to wandering around. One nurse participant [N1] explained the use of Broda chairs as common in the hospital setting and

“...our way on an acute care floor because we can’t watch them.” A family member [FM5] I interviewed talked at length to me about how her father was restrained in a Broda chair because “they didn’t want him moving because it was you know, they didn’t have the ability to monitor him...right?” This family member also described how her father, when not sedated, was often confined in his room by the limits of the chair that he was sitting in. As she stated,

...they started to put him in his room and they would either block it by moving the bed.

So he could still move his wheelchair in the room with his feet but he couldn’t get out.

And then they started just putting his brake on and so you would arrive and he would be stuck facing a wall or the window. [FM5]

One of the nurse participants [N1] also discussed the use of Broda chairs as a restraint, which she found quite upsetting.

And I always say to people, “Well, how would you feel if you’re shoved in a chair?” And people are left in the chair 24 hours a day, seven days a week. They take them out, change them, put them back in. Because they try to get out (of bed) so they don’t want to run down and get the bed alarm all the time.

In two of the units that I spent time in, it was difficult for patients who were confused to be able to walk around freely. This was not the case on the ACE unit, which was a locked ward. I regularly observed patients in the ACE unit wandering up and down hallways and into patient rooms that were not their own. This was tolerated by staff, and even by other patients. During the time that I spent with Mr. Powell on the ACE unit, there was another patient on the ward living with dementia who wandered into his room several times throughout each day. Mr. Powell and his wife got to know him a little, and Mr. Powell’s wife would bring chocolate whenever she was visiting to share with this patient. I saw this patient in another patient’s room one morning,

standing by the bedside and providing comfort to the person lying in the bed. Staff were used to patients who were confused walking around, and did not worry about them leaving the unit and getting lost and this seemed to foster an environment where restraints were not needed as often. I asked about the possibility of a patient like Mr. Chiang being transferred to the ACE unit, where he would be able to move about more freely but was told that as an ALC patient, he did not meet the criteria for admission to this unit. It seemed that if a person was admitted to the ACE unit, and then later was designated ALC, that they could remain on the unit. However, a person already designated ALC on a different unit would not qualify for the ACE unit, even if they might benefit from the ward's set up.

Placing a person in a chair that they cannot move out of is a powerful form of restraint in and of itself. Ironically, one afternoon when I was spending time with Mr. Chiang while he was sitting in his Broda chair, I noticed a sticker on the tray that warned against using the chair as a restraint. This observation occurred during the time period when his functioning seemed to be declining. At this point, his Broda chair was keeping him in place, and likely contributing to his deterioration.

Mr. Chiang is reclined in his Broda chair in his usual spot in the hall. He is sleeping deeply, mouth slightly open. I spoke with a care aide who knows him well. She told me that prior to today, she heard that he did not sleep for 48 hours and that during that time, he was "bad", tearing at his pads, hard to settle. I mention to her that his face seems more drawn and she tells me that she wonders the same, and mentions again that is not eating as well as he used to. I notice where I'm sitting that I can see a sticker on the underside of the tray. It is a warning sticker: "This tray should not be used as a restraint" [FN: 02.05.2020]

It should be mentioned that it did not seem that everyone who used a Broda chair found it uncomfortable or distressing. For instance, Mrs. Rogers seemed quite content to sit up in her chair, and it was convenient for her to have items on the tray in front of her, particularly with

respect to the left-sided weakness resulting from her stroke, as she could easily reach out and pick items up. Mrs. Wong also appeared to be quite comfortable in her Broda chair, certainly her husband appreciated that it kept her situated in place, as she tended to move about quite a bit when she was in her bed.

Mrs. Wong's chair is a padded contraption, a white plastic table encases her. Her husband says that she is safe in this chair for in bed she can move about quite freely. There is a cushion for her feet and her lap, and her feet are covered by a flannel blanket. She is nicely tucked in. [FN: 10.29.2019]

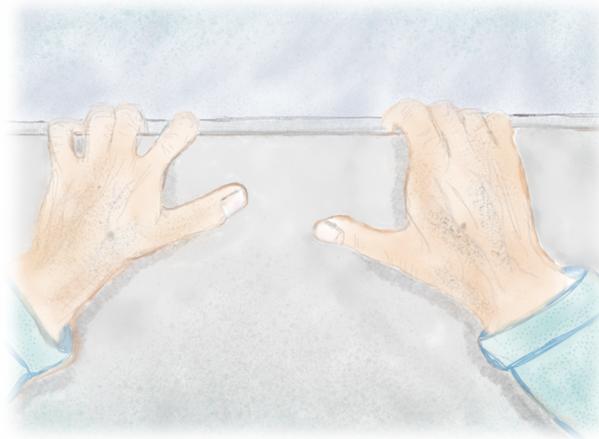
However, I did observe participants obviously unhappy about the constraints imposed by the Broda chair and its accompanying tray. One of the nurse participants [N1] spoke of how patients do not like the Broda chair, particularly the tray attachment that is usually used. As she stated, "And as soon as you get someone in a chair, the first thing they'll say is, "No table." Because they know that restrains them." Certainly, I observed Mrs. Ho exhibiting what appeared to be frustration with the tray, which was often snugly put in place against her stomach. Her daughter told me that this was so that she could not reach her Foley catheter and pull on it. In her case, it was clear that the chair and tray were effective restraints. She was unable to move much in terms of repositioning herself, and while her hands and arms were free, she was unable to reach far, as the tray prevented her from bending forward.

Suddenly, she leans back and emits a big sigh and begins to run her hands along the edges of her tray, as well as under the tray. Perhaps she is feeling confined? She continues to do this for a bit and tugs slightly at the tray, unable to make it move. She leans back again, sighing again. Her movements seem more agitated now...She suddenly slaps her forehead twice...at one point...she bangs her tray with her hands. [FN: 11.01.2019]

I observed Mrs. Ho physically reacting to the restraining tray on another occasion:

She puts her right elbow in the space between her tray and her body below it, she uses her elbow as leverage to ease some of the pressure from the tray...Her eyes are open wide in

concentration and her chin is jutting forward as she does this. She has managed to get her right hand under the tray now and is banging her fist under it, and uses her left hand to slap the surface twice. While she's doing this, it seems to me that she has entered her own space...she does not look at me or talk to me during these times. She seems quite intent of what she is doing. I see the tray shift a tiny amount, but it is securely tied with a strap that connects behind the chair. [FN: 12.20.2019]



**Illustration 5: Gripping the Broda Tray**

Mr. Chiang was another patient participant who spent a lot of time in his Broda chair. He was mobile with a walker but was at risk for wandering, and also could get agitated easily if redirected by staff. Having him sit in his chair was a way for staff to both keep an eye on him, and prevent him from wandering into areas where he should not be, such as into the nursing station. Unfortunately, I witnessed several instances where he became very frustrated and angry about being restrained in his chair. As mentioned, both he and his wife Mrs. Chiang were hospitalized on the same ward. Mrs. Chiang, who could walk about freely, would often come and sit by her husband, and he would frequently ask her to remove his tray, which would prompt her to get up and start to tug on the tray causing his chair to shake, and his frustration to mount. As this usually occurred while he sat in the hall by the nursing station, the staff were able to respond quickly to reassure them and prompt her to stop pulling on the tray. However, at times Mr.

Chiang's frustration with the tray and inability to get out of the chair on his own would cause him to become very agitated. I recorded the following observation during one such occasion, when he was seated on his own in the hall.

Mr. Chiang notices his walker, which has been placed in front of him when he was last brought to the toilet. He leans forward and tries to move it, managing to shift it slightly into the hall. "Mr. Chiang, stay there!" a staff member says as she walks by and goes into the staff room. "Hallo! Hallo!" he says, showing his magazine to staff who are by the nursing station, shaking his walker. "Hallo!" he calls again. "HALLO!" very loudly. "Yesterday he was calm," I hear someone say at the nursing station. "HALLO!" he shakes the walker, banging it on the ground. He points his finger at the staff at the nursing station and makes punching motions with his hand. A staff member comes by and moves the walker away from him with her foot. She walks by him and points her finger at him. "Shhh!" she says. She looks at the MAR on the med cart. "I'm going to give him Loxapine," I hear her say. "HALLO!" he calls again....The nurse walks by Mr. Chiang and he tries to grab her arm and she dodges him. "I don't want him to break my arm," she says. She comes up to him and lifts his right sleeve and proceeds to give him an injection. He does not react at first but after she draws the needle out, his face crumples and he grimaces. "Don't cry now," I hear someone say. He picks up his magazine again. [FN: 01.20.2020]

Mr. Chiang shared a two-bed room with Mr. Hastings, who frequently witnessed his roommate's challenges. One morning, after Mr. Chiang had experienced a particularly difficult night where he was up and calling out for much of it, Mr. Hastings and I discussed what this was like for him. He told me that he had "some empathy" for Mr. Chiang and said to me that, "I think he is afraid". He recognized that Mr. Chiang likely felt restrained, and also felt that part of the difficulty could be attributed to the fact that staff could not always communicate with him in his own language.

While Mr. Hasting was not restrained in a Broda chair and routinely walked around with his walker, he talked about feeling restrained while hospitalized. Although, he was able to walk around the unit, he told me in one of our informal conversations that he did not like that he could walk about as freely as he wanted to. He reported feeling "claustrophobic" and told me that he

felt “detained”. Staff watched him carefully when he was walking about as he often forgot where his room was, and could at times walk into other patients’ rooms or the staff room. At times, he could get irritated with staff if he felt that they were directing him and telling him where he could walk. One afternoon, during one of our informal conversations, he described to me being recently restrained in what he described as a police chair with a large belt around his waist, and how this had been very upsetting for him. I was not aware of Mr. Hastings being restrained in a chair during his hospitalization at the hospital setting where I got to know him. He was one of the patients who had come from another hospital site, and this could have been a memory from previously. It could also have been a confusing thought related to his ongoing delirium, perhaps related to having observed his neighbor Mr. Chiang restrained in a chair. Regardless, it was a powerful description of the distress related to being restrained in place.

#### **7.4.2 I am medicated**

It was not uncommon for me to be observing people at rest, as often participants were sleeping when I happened to come by. Patients napped, often after being awake or up in their chairs for a period of time, sometimes catching up on rest if they had not had a good sleep the night before. Other times, participants slept because they were simply exhausted after experiencing a difficult care experience, as was often the case for Mrs. Ho following her catheter changes. However, I also observed occasions when participants were drowsy or sleeping deeply after receiving sedating medication. Mrs. Wong routinely fell asleep late in the morning after receiving her morning medications, some of which her husband told me were to help her “cool down”. As of result of receiving medications to calm him down, I observed that Mr. Chiang could have several “sleepy” days in a row, where he would sleep on and off for most of the day. On one occasion, I observed him sleeping in his Broda chair in his usual spot in the hallway,

where he lay reclined in the chair, sleeping deeply despite ongoing activity and noise around him.

He is reclined in his chair, slightly leaning to the right side, his head supported by a pillow. His feet twitch slightly in his sleep, resting on the chair's footrest. He is sleeping deeply, mouth slightly pursed, lips vibrating slightly with each exhalation. He does not rouse when people walk by or when the noise of the unit rises around him. [FN: 01.30.2020]

On another occasion, I observed him sleeping for a long stretch of time in his bed during the late morning, likely experiencing a medicated sleep following several days of problematic behaviours. During this time, he proceeded to sleep through a lot of commotion and activity in his two-bed room, including having TED stockings applied to his legs in his sleep, as well as the discharge of his neighbor Mr. Hastings and subsequent cleaning of the recently vacated bed beside him.

Mr. Chiang sleeps on, his cap on his bedside table, a pair of brown shoes under his chair, with socks tucked into them. I've never seen him wear these shoes and I wonder how long they've been there, waiting under the chair? The room is bright and his bedside light is on. The cleaner clatters around his former neighbour's bed, scrubbing the chair, the railing and the drawers. Mr. Chiang snores deeply despite the brightness of the room, despite the noise the cleaner is making...I wonder about the delayed and long-term effects of sedation? He does seem sedated as the cleaner noisily scrubs down the mattress and pillows of the bed. There is a strong scent of disinfectant and Mr. Chiang sleeps on and does not even stir. [FN:01.28.2020]

Mr. Lee's daughter disclosed to me concerns that she felt in terms of the hospital team medicating her father.

She confides in me that she thinks that the team wants to send him home as soon as possible because of his aggression. She talks about how she's eager to take him home, particularly as she's concerned that they will medicate him to control any aggression or difficult behavior. She says that here in hospital, that he "loses control" and she's worried that they will tranquilize him. [11.14.2019]

One study participant, a family member [FM5], shared her father's experience as an ALC patient living with dementia. Her father had been an ALC patient at another hospital, and it had

been over a year since this has occurred. However, her memory of finding her father routinely medicated was still quite vivid. As she explained, “He was being overmedicated so sometimes you would walk in and he would be drooling. Non-responsive. Snowed. And he’d be like that for 24 hours. And our comments to the staff at the time was, I don’t know what happened last night but you snowed him!” This family member also described how medicating her father led to a challenging and ongoing cycle of confusion, agitation and sedation. Once her father would emerge from sedation, she found that he could be quite confused, could act out as a result of this confusion, and find himself medicated again. She brought up the damaging and detrimental repercussions of this cycle.

And how....you know, he’s supposed to be maintaining his strength here. He’s not eating. You know, you’ve got him sitting in a chair or lying in a bed in this manner. He’s not engaging with anyone. How is this helpful? He’s not walking, right? He’s sleeping the whole 24 hours and then he would have to come out of this fog and again, “Where am I? What’s happening?” And I’m sure there was combativeness there in which case they would snow him again. [FM5]

One of the nurses [N1] talked about the tendency to resort to using medications and other restraints when patients act out. As she stated, “...I find as nurses we just go right to the easy fix. The medications, let’s just put wrist restraints on.” She found that focusing on patients’ unmet needs helped, such as helping patients to the bathroom regularly or providing them with the opportunity to walk around the ward. As she explained,

I will walk my patients, I’ll make sure they’re toileted. If it’s someone who is confused or has dementia, toileting them if I know that’s one of their triggers, toilet them every two,

three hours..you know, so I get a lot of resistance because I find a lot of the times, people are just...they want convenience within nursing, right? [N1]

In her experience, taking care of patients' needs helped them to feel settled and behaviours would improve, and she found that she would not have to resort to medications as much.

## **7.5 Chapter Summary**

This chapter has provided an in-depth look at the distress that ALC patients living with dementia can often experience as part of their hospitalizations. I do not think that the patients thought that they were behaving badly when they yelled or called out, or reacted physically to the situations they found themselves in. Nevertheless, they were often seen as behaving badly, and labeled by distinct signage that singled them out as difficult patients when their behavior was deemed unsafe. The physical and emotional toll of distress on the patients is unmistakable, and while difficult to witness and describe, are an important part of the patients' hospital experiences. The patients' distress also had a profound effect on staff and family members, although their stress and concerns are secondary in the context of this particular work, by virtue of it being focused on the patients themselves. While the patients' distress is indelible, the following chapter's focus widens and moves away from this chapter's emphasis, in order to consider the patients more fully as people who are more than just the diagnosis of dementia, behaviours and the designation of ALC.

## Interlude V

### The Kindness of Strangers<sup>8</sup>

She looks at me when she starts to eat  
I could tell that she was trying to offer me some  
Spoonful of her fruit out of the bowl  
And offering it to me

I say hello, and she says hello,  
Grasping my hands.  
I ask if I can sit with them,  
And she makes space for me by her side.

She contemplates her plate  
And starts to speak to me  
I think she want to share her lunch  
As she takes her fork  
And evenly divides the food on her plate  
Into two portions

I come to say goodbye  
And she jumps up from her chair  
She pats my back and  
Tries to offer me her chair  
I decline, say thank you  
They wave goodbye as I leave

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<sup>8</sup> Written with excerpts from Field Notes for Mrs. Chiang 01.14.2020-01.17.2020

## Chapter 8:

### Expanding the Aperture - Looking Beyond ALC Designation

*I would like to talk about politics for one thing, what people are thinking, things like that!*  
(Mrs. Rogers)

#### 8.1 Overview

One morning, I came onto the unit to see that Mrs. Rogers was sitting in the hallway by the nursing station. She was having a snack, holding a piece of chocolate in her hand, and was sitting in her Broda chair, smiling as she watched the activity of the ward around her. One of the staff members walked by, and seeing her there said “so cute!” I was not sure if Mrs. Rogers heard that comment and if she had, what she thought about being called cute. I also asked myself how often I might have thought an elderly person or patient was cute, and perhaps uttered similar words, either out loud or to myself. I must admit, that I likely have. Another comment that I heard often from other people about the patient participants, usually from family members, was that their family member became quite childlike as a result of being hospitalized, as well as due to their dementia diagnosis. Various family members made comments to me such as “he’s/she’s like a kid” or “it’s like a nursery in here”. These comments did not seem to be ill willed or derogatory, but rather a remark on the changes that they had observed in their family members over time, and the increased needs they now had as long-term hospital patients. Nevertheless, these types of descriptors do play into common societal and stereotypical beliefs that tend to infantilize older people. I caught myself making a similar observations writing in my field notes, during a session of observation with Mrs. Wong, when I remarked on the following:

She looks like a child, curled up on her side. Tiny feet, ankles exposed, pink but slightly dry and cracked skin. [FN: 10.24.2019]

That older people are viewed through the lens of “cuteness”, or seen as childlike as they become more dependent on others over time, especially when there is a dementia involved, is nothing new. Nevertheless, this chapter challenges these common perceptions of being old and living with dementia, and is focused on looking beyond the trappings of old age and dependency that can be hard to see beyond, especially in the hospital setting. As such, this chapter explores the agency and personhood of the participants, their strengths as individuals and what is important for them as they deal with an extended hospitalization. The following themes are explored in this chapter: There is More to Me Than This, What Makes a Difference to Me and Finding Moments of Connection.

## **8.2 There is More to Me Than This**

This theme reflects the fact that the patients who took part in the study were more than simply study participants and ALC patients living with dementia. While family members might have found their family members childlike at times, they also took the time to tell me personal details about the participants, revealing many aspects about them beyond their current identity as ALC patients. Many of the participants were immigrants who had come to Canada to start new lives and raise families. Others had deep connections to their communities, having lived in the same area most of their lives. They each were individuals with their own histories, some having lived through traumatic and difficult life events. Many had worked in professions such as business, insurance and medicine. All had children and grandchildren, and most were still connected and close to their families. As individuals in their own rights, the patient participants had their own stories, and despite the challenges that many of them experienced because of advanced dementia, they were resilient human beings with their own sense of agency.

### 8.2.1 I have my own story

Several family members shared photographs of the patient participants with me, eager to show me who their family member was within the familial and familiar context of their lives. When I saw these pictures, it was a good reminder of the totality and fullness of people's lives, an aspect of people's selves that can be easily obscured in a hospital setting. I recorded the following fieldnote after Mrs. Ho's daughter showed me pictures of her mother taken in the years and months prior to her hospitalization:

I see pictures of Mrs. Ho with her family, hair nicely coiffed, neatly dressed in a backyard surrounded by family, and at family dinners posing with family members. It is nice to see her in her own context, hale and well. I don't know if she has dementia in any of the photos but this does not matter. Here in the hospital it is clear that she is "unwell"...in her hospital pajamas and gown, with the aggression sign by her bedside, often with particles of food in her mouth...the contrast is stark and is a good reminder of the full person she continues to be, despite the particular context I know her in. [FN: 11.07.2019]

Similarly, I saw pictures of Mr. Lee, who, until his dementia worsened, dressed in a suit and tie most days. One of his daughters also told me about how he used to savour and enjoy his meals, and was a connoisseur of good food. During the time that I spent with him, Mr. Lee only wore a hospital gown, often with a second gown front to back over top. He had a good appetite, and as his daughters sadly reflected on, happily ingested the pureed meals that were provided for him on his hospital tray. However, he always had an elegant mien to his posture, sitting in his Broda chair with his hands clasped together resting on the chair's tray, looking around and watching the world around him. Despite the changes attributed to his dementia, and exacerbated by his long hospitalization, I could see the elegant gentleman who was Mr. Lee. As one of his daughter's told me, "everyone has a story behind them" and the more time that I spent with patients and their families, the clearer this became.

Patient participants who were able to converse in English with me, also frequently shared personal details about themselves, emphasizing that there was more to them than their status as an ALC patient living with dementia. For instance, Mr. Hastings described himself as “an easy and roaming guy”, and over several occasions, he shared aspects of himself with me in regards to his business and his life on one of the province’s small islands. He had lived there independently prior to his hospitalization, and had been running his own self-started business. As previously mentioned, in addition to his dementia, he was also dealing with a chronic delirium, which meant that at times he would see animals and people who were not really there, and he could get quite confused. However, despite these challenges, he was able to share parts of his life’s story with me, and was very clear about what things were important and meaningful to him. As a result of this, I could see how his previous independent lifestyle and entrepreneur-like nature could cause him to chafe at being hospitalized. He very much wished that he could return to his own home, and was at times quite cognizant of the fact that decisions were being made on his behalf by others, especially when it came to being waitlisted for facility care, and he could clearly articulate to me that this was very difficult for him to accept.

Knowing more about the patients’ customs and preferences also helped me to understand activities and habitual actions that they engaged in while hospitalized, that could simply be attributed to their dementia, but actually revealed personal aspects about themselves. For instance, several of the patients would occupy themselves with folding towels and other items, or cleaning-like activities, often repetitively. As described earlier, Mrs. Ho could at times occupy herself with wiping down her Broda chair’s tray. Her daughter told me that she had always been a very active person, cleaning her home carefully, caring for family and cooking for the people around her, prior to her illness. Similarly, Mrs. Wong’s husband told me that she was a very neat

person, and had always kept their home very tidy, and I began to see her regular fidgeting and cleaning-like actions quite differently, as revealing aspects of herself rather than just as symptoms of her dementia.

### **8.2.2 I have agency**

Over the course of my observations, I was also able to see how the patient participants were able to exercise agency at different times, and in their own individual ways. This was something that I noticed across all of the patient participants, who lived with varying degrees of dementia or cognitive issues. Manifestations or expressions of personal agency varied, in some instances it was clear to see or hear, or in others, it was more subtle in nature. For instance, Mr. Powell, who experienced confusion at times, but did not have an official dementia diagnosis, was able to clearly express his wishes to staff. He could let them know when he was tired and wanted to go back to bed. Expressing his needs to others was more challenging for Mr. Chiang, as he could not speak English. Staff knew that he did not like to be restrained in his chair, and his reactions to being stuck seated have been described in the previous chapter. When Mr. Chiang called out or pulled on his tray, it was often seen as a responsive behaviour, which is quite likely given that while he may have been experiencing an unmet need, such as needing to go to the bathroom. However, he was also likely experiencing fear, anger or anxiety at being restrained and could have been trying to express his feelings to others. A care aide who worked often with Mr. Chiang and spoke his language shared with me the following interaction with him, demonstrating his ability to make his needs and desires known.

She tells me that he is saying that he wants to go back to bed. She says to me that “he knows what he wants” and that a few days ago he told her, “I’m old, let me rest” when he insisted on being allowed to keep sleeping. [FN: 01.28.2020]

I was not able to communicate with Mrs. Ho in her own language. However, despite her dementia and the different languages we each spoke, I noticed that she was able to make her needs known to me during the time we spent together. I would often speak to her in English, even though I knew she might not understand me, along with using other strategies to communicate with her.

I asked Mrs. Ho if she would like the head of the bed raised, knowing lunch was coming and thinking that it was difficult for her to visit with me lying flat on her back. I made physical motions demonstrating raising the head of the bed and she seemed agreeable. I raised the head of the bed about 20 to 30 degrees and she seemed pleased. I also motioned to the bed curtain asking her if she'd like it opened, knowing that she enjoys watching the comings and goings around her. However, she started to shake her head when I opened the curtains slightly, so I closed it again and she smiled and gave me two thumbs up. [11.26.2109]

Mrs. Ho also never shied away from expressing her opinions about how she felt about staff:

She notices him and she points her finger at him as he leaves, frowning. She looks at me and makes a swiping motion a few times in the air with her left hand as if saying that she does not like this nurse. [FN: 01.08.2020]

Her daughter had told me that she liked some nurses more than others, and although her actions above could be interpreted as simply an indication of preference and her opinion of that day's nurse, I also felt that she was exploring her position in her current social world. She did not think much of the nurse, and she felt free to express this opinion in her own way, as a patient receiving care from that person.

There were other interactions that I observed where I felt that patient participants were trying to express themselves and make their needs known, but because of communication challenges, the opportunity to acknowledge and respond to the person was missed or ignored. I witnessed the following when spending time with Mr. Lee:

He looks over at his bedside table that has been left at the foot of his bed. Earlier, when the second nurse installed it there after providing care, he had pointed at it. There are two water cups, a soap dispenser, a cream and a folded bib on it. The nurse had noticed him

pointing at it, had lifted one of the cups up slightly to offer it to him, but then put it back on the table and walked away...[FN: 12.23.2019]

I wondered after if Mr. Lee was thirsty and wanted a drink, and felt bad about the half-hearted attempt that the nurse had made to try to understand what he wanted and was trying to indicate. I noticed that Mr. Lee, as a non-verbal person, did not often initiate interactions with staff by pointing or trying to communicate with his hands. He might also have stopped trying to initiate interactions because others would not understand him, or make the attempt to understand him. I realized that agency can be embodied, and sometimes expressed in very subtle ways, and that it can be exhibited in ways where a person can simply be trying to make a need known.

Despite his dementia and his delirium, Mr. Hastings was quite aware his upcoming move to a care facility was a decision that was being made on his behalf by others. One on occasion, I observed Mr. Hastings talking with his daughter about getting ready to move to a care home. He told her that “I don’t agree with it” in terms of the plan for his move. Later, after his daughter left the room, we had this interaction:

His daughter goes to sign the paper work and he looks at me when she leaves and says, “Well, things are changing in the world.” I ask his what he means and he tells me, “they are transferring me to an extended care facility next week.” I ask him how he feels about this. He tells me, “I’m not happy about that.” [FN: 01.24.2020]

### **8.2.3 I am resilient**

Despite the challenges that the patient participants experienced over their long hospitalizations, many of them demonstrated remarkable resiliency. This was not to say that their abilities and wellbeing were not affected by their hospitalization experiences. As previously discussed, I witnessed physical deconditioning and emotional changes as time went on, particularly for those participants who spent the longest periods of time in hospital. However, the participants were also resilient, many in their own ways, as they tried to find ways to manage

difficult and long hospital stays. Mr. Powell, after many months of hospitalization and several weeks as an ALC patient, found out that a bed in a care home was being offered to him. He was pleased, as this was a care home on his preferred list. When he was not able to move due to his sudden infection he told me that he tried to “stay positive” and preferred to “take it as it comes”. Throughout his long hospitalization and this significant setback, which meant that he ended up staying in the hospital for several more weeks, he remained positive in his outlook. Similarly, Mr. Hastings explained to me that while he could feel frustration at his situation, it helped “to bend with the wind”, as a way to cope with some of the challenges he was facing.

In some cases, resiliency was revealed in simply enduring an extremely long hospital stay. Mrs. Wong was in hospital for so long that her hospital ID bracelet became so worn and old, that there was no longer any legible text on it, effectively becoming a blank ID bracelet. Yet, she persevered and eventually was transferred to a care home after nine months in hospital, seven of which were as an ALC patient. I heard from her family shortly after her discharge, and from another family that ended up in the same care facility, that she was faring very well in her new home and had begun to thrive.

Earlier I described Mr. Chiang’s physical decline as he spent more and more time in his Broda chair, as his ability to mobilize on his own deteriorated and he began to experience lower leg edema. As I also mentioned previously, his care plan was altered at one point towards the end of his hospitalization as staff began to let him sit in a wheelchair without restraints, and allow him to get out of the chair on his own when he felt like it. They kept an eye on him when he walked around with his walker and ensured he did not walk off the unit. I made the following field note when I arrived back at the unit to spend time with him, after having been away for several days.

He is walking around with his walker by the entrance of the ward when I arrive. I smile widely to myself when I see him. It's good to see him up and about. I say, "Hello, how are you?" And he repeats the words back to me. He walks past me. His wheelchair sits empty in the hall, his bedside table is sitting in front of the wheelchair, the iPad playing a show. One of the care aides follows him as he walks. He stops at the closed doors of the Patient Care Coordinator and Transition Nurse's offices and tries to open the doors. Then he wanders back towards the nursing station, the care aide following closely. "He wants to walk," the care aide says that he has just told her this. He has been in his wheelchair all day, and the Broda chair has not been needed, one of the LPNs tells me. He also tells me that he has been wandering about a lot lately and he even sat in with the student nurses during their debriefing earlier...He has walked back up the hall and has entered one of the patient rooms. The care aide follows him. It's nice to see him walking around, even one of the hospital cleaners who I have often seen about says to me, "he's walking" and that "he doesn't like sitting in the chair". We remark on how nice it is to see him up and about. The care aide takes him into his room to the bathroom. I take this opportunity to ask another care aide how he's been doing? She says that he has been calmer because he is now more mobile. The change in care plan has made a difference she says. "He's more directable," and she explains that he tends to do well with people who can speak his language and who he is familiar with. [FN: 02.14.2020]

While it was encouraging to see that a care plan change had made such a difference to him and that he did not have to be restrained in his chair for long periods of the day, what I was most struck by was his resilience. He was elderly, had been in hospital for many months coping with not having much to do, unable to move much and feeling quite upset a lot of the time. Yet here he was determinedly walking the halls, exploring his surroundings. When I returned a few days later, I found him in his Broda chair once again, and was informed that at times he still had to sit and be restrained as he was walking into spaces where he could not be, such as patient rooms, a little too often. Fortunately, he was discharged to a care home a few days later, where hopefully he was going to be able to walk around more freely and explore his new surroundings.

### **8.3 What Makes a Difference for Me**

Whenever possible I asked the patient participants what it was like for them to be in hospital, often asking them what a good day was like for them. I also asked them what, if any,

bad days were like. I got a variety of responses, and sometimes it was hard for people to answer.

Prior to this, before I left her side, I have asked Mrs. Rogers what a good day was like, and she said “any day” and when I asked what qualifies as a bad day...she paused and seemed unable to answer, then said “I don’t know”. At this point, she caught a glimpse of her neighbor going back to bed and said to me that he is difficult, but could not elaborate other to say that he complains a lot. She then tells me that the “men here complain more than the women!” I ask her if this surprises her, and she says, “yes, actually” before drifting off to sleep. [FN: 11.19.2019]

In my interview with Mr. Powell, he told me that he did not have any bad days, although he did mention that he felt frustration at times as a patient waiting for facility. Good days in hospital for him included having “a good breakfast”, having regular bowel movements, and getting a chance to go for a walk. Mr. Hastings told me that a good day for him occurred when people came to visit him. He was independently mobile with a walker but had a tendency to “wander”, sometimes walking into the staff room, other patients’ rooms, and one time taking himself off the unit. Staff had to watch his movements to ensure that he did not walk off the unit and get lost, and he was aware of this restriction and monitoring of his movements telling me that he did not like that he could not walk around as he wished. Mrs. Wong’s husband shared with me that a bad day for her was when she had not had a bowel movement for a few days. She also did not like to have her head and hair touched, so days when she had a full shower tended to be “trouble”, as he put it. While each participant experienced good and bad days in different ways, how basic body functions were attended to tremendously affected the patients’ experiences, both in good and bad ways. This theme of What Makes a Difference to Me reflects the idea that basics matter for ALC patients, and that there are benefits in finding ways to connect with patients, as well as taking the time to listen and talk to them.

### **8.3.1 Basics matter**

The more time I spent with patients, the more it became clear that having basic care

necessities attended to, particularly around matters of excretion, really mattered to them. Being able to have regular bowel movements, as well as being able to void regularly and in comfort really made a difference to patients, and affected how they felt and reacted. For instance, I witnessed the relief and content that Mrs. Wong experienced after being able to properly clear her bowels.

She's sitting up in bed, smiling and laughing. Her husband says, "she is happy!" As her husband ties her gown over her pajamas, she laughs. She must feel so relieved, her spirits are high! [FN: 10.29.2019]

In contrast, she struggled with the incontinence pads she had to wear on a daily basis, finding them irritating, causing her to frequently pluck at her clothing and attempt to disrobe. Clearly, as discussed earlier, the inability to void without a catheter created extreme challenges for Mrs. Ho, causing her much distress and discomfort, particularly the frequent insertions of the catheters. While Mr. Chiang disliked being restrained by his tray, he could also get quite upset when he needed to void and could not get up to do so whenever he felt the need to. He routinely wore incontinence pads, but unsurprisingly preferred to be able to void on his own in the bathroom. I was able to observe how upset he could get if he felt that he could not take care of this very basic human function in a timely fashion. Staff members were aware that he could get upset when he needed to use the toilet, and tried to respond quickly when he started calling out. However, his frustration at not being able to immediately get up and void when he needed to was significant.

Now he is yelling again, "Hello!, Hello!!, HALLO!" he calls looking around. "Washroom, washroom.." he calls as a staff member walks by. "Washroom!" he says again as he bangs his tray. A nurse comes to take off the tray to his chair and another helps him up with his walker. He is assisted into his room to use the washroom there...Mr. Chiang returns accompanied by a staff member. She helps him to sit down and puts the tray back on his chair. He assists her a little by passing her one of the tray's straps. She fastens the tray in place behind his chair. He sighs loudly, she passes him his magazine as he says a quiet, "hello..." [FN: 01.20.2020]

One of the nurse participants [N5] spoke of the importance of attending to basics. As she stated, “A good day is making sure that they eat, drink, they’re not constipated, they’re not in pain, and they sleep well. Very key ingredient for care. It’s not rocket science. It is basic care.”

Apart from bowel and bladder functions, other interventions attending to basic comforts that patients commented on included being offered a warm blanket at night, having regular snacks or a cup of warmed up coffee.

How nurses approached care mattered a lot as well. As one nurse participant explained, it makes a difference when nurses take the time to communicate with their patients and explain the care they will be providing. As she stated, “Just talk...talk to them. Tell them what you’re doing. They’re no different than anyone else.” [N1] Mr. Lee’s daughter explained to me that some nurses were better than others.

She remarks on the level of confusion in the room, telling me that three out of four patients in the room are confused. She tells me that the person in the room who is not confused reports to her that some nurses are nicer than others. She explains to me that a Chinese proverb she knows helps her to understand how care can vary between nurses. The proverb goes like this (translated in English by the daughter) “We have ten fingers, some are long and some are short” She explains to me that this means that not everyone is the same. [FN: 12.20.2019]

She told me that a good approach entailed small acts, such as compassion and a gentle approach, basic aspects of care that according to her made a real difference to her father.

Another nurse also talked about the importance of person-centered care planning which could make a positive difference in meeting client’s needs. She felt that care planning was regularly undertaken on her unit, but one of the other nurse participants from another nursing unit had quite a different opinion. As she explained,

So when you go into our care, and you know it’s someone who’s ALC, or maybe a behavioural thing, and I get frustrated because [PCC’s name] goes, “Can you do a care

plan?” And I’m like, “What’s the point?” Because, number one, no one follows it and number two, this person has been here for three months. This is the first time I’ve been assigned to them. How come nobody else is doing care plans? I don’t mind doing it but that should be on admission. [N1]

This was concerning to hear given that care planning is a basic nursing skill, a competence that nurses learn during their initial nursing education, and an important part of person-centered care.

### **8.3.2 Find moments of connection**

It was not always easy to understand what patient participants were feeling or thinking, especially for those who were non-verbal, had trouble with word finding or when English was a second language. Several of the participants could experience labile moments throughout the day, and could not always explain what they were going through. Mrs. Wong could have sudden mood changes that her husband did not always understand.

Suddenly she begins to cry. Her head bowed, she wipes at a few tears. She cries quietly. He seems to be asking her what is wrong, I hear him murmuring quietly to her as he leans forward. I ask him, “Is she okay, what’s wrong?” He shrugs and indicates that he doesn’t know. He explains, she “is in her head” and this sometimes happens to her. [FN: 10.29.2019]

However, he was often able to soothe her by reaching out and making a connection with her, which often could be done when he repeated her name out loud to her.

Often he will reach out to grasp her hand or slide his hand up one of her arms. He will say her name, he says that she likes that and will recognize her name. She doesn’t remember his name but will call him husband. [FN: 10.24.2019]

Mrs. Wong’s husband’s devotion was obvious to me each time I spent time with them both. He provided for the bulk of her care needs whenever he was present, which was for the majority of the day. He was a proficient and expert caregiver, responding quickly to her needs. The nursing staff were very appreciative of him and of the help he provided for his wife’s care.



### **Illustration 6: Connecting with Others**

I had a similar experience with Mrs. Ho, when I came into her room one late morning to find her ensconced in her chair by the side of her bed. She was quite upset when I approached her, shaking her head and pointing her finger agitatedly towards the corner of the room, trying to verbalize and making high-pitched sounds. I was not sure what wrong at first, until one of the staff members caring for the patient across the way looked over to see why she was making noise. She told me that Mrs. Ho was “so mad” because they had just gotten her up and she was not happy with this. I wrote the following field notes:

I decide to sit next to her, and when I do so she does not react. In fact at first, she is intensely glaring down the hallway. Then suddenly, we make eye contact and her face crumples for a second as if she’s going to cry...She reaches out and grasps my hand.  
[FN: 12.23.2019]

She held my hand for a few minutes while we listened to the nurses caring for the patient across the way from her, who was being suctioned and who sounded quite sick. Shortly after, she

released my hand and sat back in her chair to watch staff at work in the hallway from where she was sitting.

Many of the patients I spent time with, did not have a family member like Mrs. Wong's husband constantly at their side, although most had frequent family visitors. Thus, when patients were alone, it really seemed to make a difference when ward staff took an opportunity, however brief, to connect with them. For instance, Mr. Powell enjoyed talking to the nurses, he tried to remember their names whenever he could and would make the effort to say hello to the different staff members who would come to care for him, as well as other patients in the room. He talked about this in his interview, and it was apparent that it was important for him to connect with the people who worked on the ward. Mr. Lee, who was non-verbal, every so often would reach out his hand when I was spending time with him. I learned that this meant that he wanted to grasp my hand giving it a squeeze before letting go. I think this was his way to connect when he could not speak out loud.

Some of the nurses I spoke with talked about the importance of taking the time to connect with patients. As one of the nurse participants [N1] explained,

And just even the little bit of engagement that you have with them...whether you're just walking by if they're sitting in the chair in the hallway and you just make a little bit of conversation whether they speak English or not, you just take the time to sit with them. That seems to calm them a little bit because at least they feel...I think they would...they don't feel so alone because a lot of the times family don't come all the time, right?

One afternoon, I observed the following interaction with Mrs. Ho and one of the nurses on the ward she was on.

The nurses have completed their assessment of the neighbor across the way. They both come by to say hello to Mrs. Ho. One of them says, “oh, she’s here now, this is better,” apparently referring to the room change. “Hi sweetheart,” the nurse says to Mrs. Ho speaking to her directly. Mrs. Ho smiles and nods hello. The nurse then leaves only to return in a moment with two hand towels clasped in her hand. She is holding them balled up and shows them to Mrs. Ho. Mrs. Ho yelps when she sees the towels, she seems happy and surprised. The nurse makes a throwing motion with her hands and says, “catch!” She then throws them at Mrs. Ho who catches them in her hands...and then attempts to throw them back at the nurse when the nurse motions for her to do so. She seems to enjoy the throwing game, does not seem distressed or insulted by it. It lasts only for a moment and then the nurse has to leave. [FN: 11.12.2019]

Initially, I was surprised that the nurse was playing “catch” with Mrs. Ho, as at first this activity seemed to treat her like a child. However, Mrs. Ho seemed to enjoy this brief moment of connection, and I suspected that this nurse had engaged in this type of interaction with her before. I also had spent quite a bit of time with Mrs. Ho at this point, and knew that she would not hesitate to show her displeasure or not participate in something she was not interested in. Rather, she appeared to enjoy making a connection with another person, however brief. At one point, her daughter explained to me that Mrs. Ho found some nurses better than others, and that the “better” ones were those that had gotten to know her mother and spent time with her.

Taking a moment to make a connection with the person, whether it was to share a few words, or allowed a person to take a moment to figure out what was going on, seemed to also help when personal care needed to be given. I witnessed a nurse take a moment to connect with Mr. Chiang while he was sitting in the hallway, in a way that facilitated care.

The nurse comes up to him, it looks as if she has a prescription cream to apply to his feet. She shows him the cream and he holds it for a moment, then seems quite willing for her to pull off his socks and apply the cream to his feet. [FN: 01.31.2020]

What struck me about this interaction was that the nurse gave Mr. Chiang the cream so that he could hold it and look at it for a few moments. I recall that she pointed to his feet before taking the cream back, so that he knew what it was for. She did not speak his language but by engaging

with him and making a quick connection, where he was able to actually hold and look at the cream, seemed to pave the way for the nurse to be able to remove his socks and apply the cream. Apart from finding ways to connect to patients, it was also clear that patients wanted to be listened to.

### 8.3.3 Listen and talk to me

An important part of connecting to another revolves around the ability to listen to the other person. Mrs. Rogers and I discussed the importance of being listened to one afternoon, as well as being able to express oneself. She explained the following to me:

. . .she says to me that good care is when people are “listening to you”. I ask her if there is anything else that makes good care? And she says, “just listening...” She also says to me, “I don’t know what it is but some people are not too good at it.” I ask her if people have time here in the hospital to listen and she says with emphasis, “they *should* have the time!” [FN: 11.21.2019]

Mrs. Rogers struggled with word finding at times and I felt that for her listening also meant that she was given time to express herself and find the words she was looking for. As she was able to tell me on the afternoon before her last day in hospital:

She sips her tea that has been put in a plastic cup with a straw for a bit, then suddenly speaks, “A few people I’ve met here, like you, are nice to talk to.” She struggles a bit to speak some more, it’s obvious she’s having some trouble with word finding. “I find it so hard to talk!” She suddenly is able to say. Then she says, “There’s not people here too...don’t...A lot of people are frustrating in that way...(sips tea)...they don’t have conversations, they don’t like to talk to you about usual things...She suddenly is able to say, “I would like to talk about politics for one thing, what people are thinking, things like that!” [FN: 11.20.2019]

I was taken aback by her words and realized that likely she had not had the opportunity to talk much at times, nor always felt listened to. This had me think carefully of the importance of listening to another person, even when we are not able to actually understand the words or sounds that we say to one another. A certain amount of actual understanding is crucial when

listening to another person, particularly if the other person has a pressing need that requires attending to that they are trying to communicate about. However, I think that if the act of listening is genuine, it sometimes could matter as much as understanding. Indeed, it was obvious that language barriers were an ongoing issue for many patients and staff on the hospital units, and I did notice a difference when staff members could communicate in a person's first language, in terms of how that could reassure patients and calm them down.



**Illustration 7: Listening**

However, I know that I did a fair amount of listening to patient participants during the times I spent with them, even with patients who could not communicate with me in English. On the last afternoon I spent with Mr. Chiang before he was discharged to a facility, he was quite talkative. He chatted with me for over an hour as we sat together in the hall. I was not sure what

he was saying and sometimes would say to him, “I’m sorry I don’t understand”. However, for most of the time I listened, maintained eye contact and nodded my head every so often to show that I was listening. We even shared a laugh together when he overheard a nurse talking to a doctor on the phone who shared a similar name as his, as he reacted to this with some amusement, and it seemed that he thought at first that the nurse was talking about him. Mrs. Ho always had a lot to say to me, despite our inability to converse in the same language. As I got to know her, I realized that she liked to express what she was feeling and thinking, and I wondered at how she felt at not being understood much of the time. This was clarified for me one day when spending time with her when her daughter was present.

Mrs. Ho has been very upset today, earlier in the morning she was put at the nursing station in her chair. I asked the daughter what has been happening, the daughter tells me that she was striking out at staff this morning and she bit someone on the hand. I think Mrs. Ho knows that we are talking about her. I kneel by her side and look at her. She looks at me and chats in her language, she is quite expressive, using her hands and arms to make a point. I look to the daughter to see if she can help me understand what her mother is saying. The daughter says that her mother has said that they do not listen to her here, and that she has to make them listen. [FN: 11.13.2019]

When Mrs. Ho’s daughter translated this for me, I realized how frustrated she must have been much of the time, when she felt that the people around her were not listening to her. She had a voice that was worthy of being heard, but was not being listened to, a fact that she was very aware of and that frustrated her.

#### **8.4 Chapter Summary**

I would like the end my presentation of findings at this juncture, reflecting on what I learned from Mrs. Ho and the other participants, who as distinct and social beings, revealed much of themselves to me in the time I was privileged to spend with all of them. This chapter has focused on presenting findings that challenge common perceptions of older patients living with

dementia and that highlight the individuality, agency and resilience of the patients who participated in this study. Overall, this chapter reminds us of the import of fully considering the personhood and social citizenship of all patients who come under the care of health care professionals in hospital, a setting where it can be hard to see beyond the veneer of patient-hood, dependency and decline.

## Interlude VI

### This Morning...<sup>9</sup>

He is mostly non-verbal  
I notice that he often grasps his hands  
Together in front of him...  
Giving him a very dignified look

She comes to show me a few pictures  
In the picture he is dressed in a suit and tie  
She tells me that he always used to dress well  
Even at home

The daughter tell me  
How her father used to eat his meals  
Very slowly in the past  
Enjoying his food like a gourmet

He is wearing a hospital gown  
The front of it is quite damp  
He does not have his teeth in  
This morning....

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<sup>9</sup> Written with excerpts from Field Notes for Mr. Lee 11.13.2019-01.08.2020

## Chapter 9: Discussion and Conclusion

### 9.1 Overview

This chapter considers the findings in light of what we have learned about the patients' experiences and perspectives, discussing several of the issues and concerns that have come to light as result of this research study. Implications for nursing practice are also discussed, specifically in regards to how the care of ALC patients living with dementia can be improved. I also consider some of the limitations of this study and ruminate on the benefits of utilizing an ID approach. There are always ongoing, as well as new problems in the world of health care to address, and novel research questions to be asked. As such, in light of this study's findings, I consider possible directions of inquiry that could be explored in the future when it comes to people living with dementia and their hospital experiences. Finally, as this chapter's title implies, I conclude this dissertation with some closing thoughts.

### 9.2 Review of Findings

My task as the researcher was to bring the patients' subjective experiences to the fore, guided by the research question that was the impetus for this project in the first place: *What perspectives and experiences of ALC patients living with dementia could inform understanding of how to improve their care in hospital?* Drawing on ID as the research approach, I undertook to answer this research question by carrying out participant observations of patients and the general setting on hospital units where ALC patients living with dementia were admitted. Observations totaled 106 hours over a four-month period of field work. I also conducted one patient interview and 13 interviews with family members and nurses involved in the care of ALC patients living

with dementia. For patients who were not able to participate in a formal interview, I engaged in multiple informal conversations with them over the course of time I spent with each person. In the end, eight patients, six family members and seven nurses participated in this study. Overall, the findings chapters, and the themes and sub-themes they contain, have illuminated what it is like for patients living with dementia to be designated ALC, and to experience lengthy hospitalizations.

As indicated earlier, it is increasingly common that the patients hospitals are serving are generally older, many of whom live with concerns such as dementia (Handley, Bunn & Goodman, 2015). Hospitals are noisy places where privacy is lacking, and are not ideal environments for long stays (Rojas-Garcia, Turner & Pizzo, 2018). Furthermore, it is a well-established fact that hospitalizations, particularly lengthy hospital stays, can be detrimental to older adults' overall health and wellbeing (Dewing & Dijk, 2014; Parke, Hunter, Bostrom, Chambers & Manraj, 2012; Sofer, 2018). Older patients are at risk for significant physical deterioration and loss of functional abilities such as mobility (Bai, Dai, Srivastava, Smith & Gill, 2019; Kalisch, Lee & Dabney, 2013), and long hospitalizations are also linked with increased chance of acquired hospital infections and delirium (Handley et al., 2015). The findings in this study align with this knowledge, and are unfortunately unsurprising given what is known about hospitalizations for older people living with dementia.

However, it is clear from the findings that ALC patients, especially those living with dementia, experience hospitalizations that are quite different than non-ALC patients. They effectively must dwell for long periods of time in the acute care setting, as they wait for alternate care arrangements to be arranged. The hospital setting is a busy and chaotic environment, where it can be challenging for the patients to share space with others over the long term. There is not

much for ALC patients to occupy themselves with, and the days and nights as hospital patients are long. Furthermore, during the long periods of time where the patients wait for their circumstances to change, their health and abilities can decline. When considering the main findings, it is evident that there is a mis-fit in terms of what the hospital setting is able to offer and what ALC patients require in order to be well supported in the long-term. It is obvious that many of the findings in this study relate to the idea that there is an incompatibility between the needs of the patients as older individuals with complex conditions and the services that are available to them in the hospital setting.

A significant finding is the distress that the patients experience, many on a regular basis. They can find their hospitalizations to be upsetting and traumatizing, and can experience labeling and stigma as a result of how they express themselves and the way that they act and respond to their situation. As a result of the way they expressed themselves verbally and non-verbally, many of the patients found themselves to be restrained in some way. Despite the challenges mentioned above, it is evident that the patients are much more than people living with dementia who are designated ALC, and who may or may not have “behaviours”. This study demonstrates that ALC patients living with dementia are resilient beings with their own life stories, who continue to express agency and make their needs and wants known to others. This in particular relates to being able to indicate what matters and makes a difference to them, from having basic care needs attended to, to being able to connect with others, and importantly, to being listened to.

### **9.3 Discussion**

How I situated myself as a nurse has been critical in informing my approach throughout the research process. Similarly, the personhood and social citizenship perspectives have oriented

and guided me throughout this study. Thus, in the following pages I consider and examine this study's findings more fully, integrating the theoretical and disciplinary perspectives that have scaffolded this study from its inception to this final stage of critical discussion.

### 9.3.1 What is “ALC” care?

As mentioned previously, the hospital setting is often a poor fit for ALC patients, as long-term patients. Part of exploring the idea that there is a mis-fit, and how this can shape their care experiences, is to consider what ALC actually means in terms of the care provided, and what the patient participants' experiences and perspectives revealed about this. It is clear that ALC patients do not require acute care, yet their status as ALC patients does not clearly define the type of care they should be receiving. CIHI (n.d.) specifically defines ALC as the following: “when a patient is occupying a bed in a facility and does not require the intensity of resources/services provided in that care setting” (p. 1). CIHI even provides guidelines on how clinicians should go about designating patients as ALC. Yet, even though standardized processes such as patient pathways are widely used in health care, specific guidelines or pathways on what happens to patients once they become ALC do not exist. Overall, there is an ambiguity to the designation of ALC. This then raises the question of what it really means to require an *alternate* form of care? In the case of the patients in this study, alternate care seemed to imply a period of waiting, a passive phenomenon whereby they are waiting to “be placed” or to have services “put in place”.

From a social citizenship perspective, the passivity of the waiting that patients experienced is problematic. Older people living with dementia are often “positioned as passive actors, due to the disabling effects of dementia on cognition and communication, thereby denying the possibility of active citizenship” (Brannelly, 2011, p. 663). For ALC patients living

with dementia the ambiguity of their status and of the care they are receiving, along with the waiting that characterizes their hospitalizations, undermines their status as social citizens. In fact, it could be argued that there was a passivity shared by many involved in their care, particularly by nurses. While this was not characterized in the way that discharge plans were actively being explored or how daily care was duly delivered, this was evident in the manner in which those involved in their care were also waiting for alternate arrangements to be put in place, and in doing so, shaping the patients' care experience. For instance, this shared waiting on the part of nurses was accompanied by a sense of resignation, revolving around an understanding that the patients could be challenging to care for, and that physical decline and behavioural difficulties were inevitable. There was a weary acceptance by nurses that the patients would likely be on the units for long periods of time. There was also the acknowledgement that the patients' needs were not well suited to the acute care setting, and as a result staff would simply do the best they could to care for them.

#### **9.3.1.1 Right patient, wrong patient?**

Overall, it is obvious the hospital is not designed to provide a home-like environment for people who must stay within its confines for long periods of time, particularly those who are older and live with dementia. I state this acknowledging that it is not the purpose of a hospital to provide homes for people who for the time being have nowhere else to go. However, in considering the idea of fitting into the hospital setting, an important question is: What is the right kind of patient for the hospital? Furthermore, is there such a thing as an ideal patient who fits in perfectly, and from a nursing perspective, is it fair, appropriate, or even ethical to position some people as being the right kind of patients, while others, such as older patients living with dementia, as not?

From an administrative point of view, there may be such a person as a “right patient”, likely one whose health needs can be efficiently addressed and who can be discharged home as soon as hospital care is no longer needed. As Parke and Chappell (2010) state, this group of patients “demands little from hospital employees, has a predictable illness course, and leaves hospital when expected” (p. 120). This was not the experience of the patients in this study, nor is it often the case for many older people who live with complex health conditions and who are hospitalized, regardless of whether they are designated ALC or not. Overall, it was clear from the perspectives of the patient participants in this study that they found the hospital setting difficult to deal with. From their perspective, it seemed that the hospital setting was not a good fit for them, and this is important to consider from the health care user’s point of view.

This sense of older adults not being the right patients for the environment that they find themselves in has been explored in other work that focuses on older adult care in the hospital setting. For instance, Tadd and colleagues (2011) undertook a study in the UK that explored older adults’ care experiences, and found that a very common perception shared by hospital staff is that older people are the “wrong patients” to be in hospital, and that the acute setting is not the “right place” for them to be. However, in acknowledging that the patients might be the wrong patients for the environment, there is the risk that it could seem that blame is being placed on the patients for not fitting in. To be clear, it is not their fault that they are using acute care resources, and that they are forced to stay long term in a setting that is not set up to meet their needs. Rather, it is important to consider what is happening to them when they become ALC patients. Is there a way that they can fit in better? This of course begs the question as to whether they should be “fitting in” in the first place, for it can be argued that it should not be incumbent on them to conform or meet the requirements of the system.

### 9.3.1.2 Challenges in providing “alternate” care

Overall, there are a number of issues that are inherent in our health care system, such as insufficient resources and the pressure to provide fast-paced care, that can inhibit nurses’ and other health care professionals’ abilities to provide quality care to patients living with dementia (Digby et al., 2017). This was reflected in the research findings in the way that nurses talked about being too busy and not having enough time to provide the kind of care they knew their patients required. It seems that there is a conflict of different interests within hospital contexts, for while health care staff may want to provide a certain quality of care, “these motivations are frequently compromised by systemic and organizational factors...” (Tadd et al., 2011, p. 35). Of further note, Maben, Latter and Macleod Clark (2007) explain that there are “covert rules” within practice environments that nurses are expected to follow, which include an emphasis on physical care to the detriment of psychological care, not getting involved with patients emotionally, fitting in and not “rocking the boat”. These kinds of implicit regulations emphasize the pressures nurses must deal with in order to assimilate within existing organizational culture and structure, often to the detriment of patients with more complex care needs.

While I did not find that nurses and other staff felt that they were worrying about “rocking the boat”, nor that they were always disinclined or prevented from emotionally connecting with patients, there was a shared acceptance on the part of nurses that the challenges inherent with caring for ALC patients living with dementia were for the most part inevitable. This was apparent in the nurse’s comment “[if] you don’t use it, you lose it” and that it was not surprising that patients like Mr. Chiang’s abilities were deteriorating. It is important to note that research is showing that the needs of patients living with dementia are often seen as less of a priority, and it seems that there is “a lack of valuing people with dementia, or a (perhaps

inadvertent) culture of devaluing of individuals with dementia in acute hospital settings, thereby disregarding their needs, personhood and emotional well-being” (Dewing & Dijk, 2014, p. 111). As such, it is important to critically question how much of what ALC patients are experiencing is a result of a culture of devaluing certain types of patients, in particular those who are seen as not “fitting in”. It should not be inevitable or acceptable that older adults experience devastating decline to their health and wellbeing as part of a long hospitalization. Nurses and other health care providers should not be resigned to or accepting of the notion that patients living with dementia will have challenging behaviours, and will struggle in the hospital environment. Unfortunately, this seems to be the case.

### **9.3.1.3 Failure to maintain**

Overall, what should be expected for people who are required to reside long term in a hospital? What is our duty to these individuals as nurses, health care professionals and members of society, when we passively participate with them in the waiting process? In this regard, it is necessary to unpack how we position the people we care for within our hospital systems, especially patients who are older and live with dementia. I will discuss the implications of labeling patients later on this discussion, as well as what it means to physically and metaphorically “place” people. However, what I want to stress at this point in the discussion is if it is expected and accepted that patients will decline, there is then little motivation to take measures to ensure that this does not happen in the first place.

This type of occurrence in care has been described as “‘unintentional tolerance’ or ‘benign neglect’ of functional decline of older patients” (Bail & Grealish, 2016, p. 151). In fact, Bail & Grealish (2016) have posited a conceptual framework that they call *Failure to Maintain*, characterized by nurses rationing care for older patients with more complex needs, which occurs

when nurses neglect or leave unfinished basic patient needs such as mobility, toileting, hydration and communication. As Bail & Grealish (2016) state, “Older hospitalized people who have complex needs, such as those with dementia, are more likely to experience care rationing as their care tends to take longer, be less predictable and less curative in nature” (p. 152). It could be that ALC patients, particularly those living with dementia and with complex care needs, could be at risk for failure to maintain. Certainly, the ambiguity surrounding the nature of “ALC” care, particularly in the way that it is characterized by the waiting for the next phase in patients’ lives, does not help.

Much of this likely relates to the ageism and stigma that come with being an older person, especially one that is living with a dementia, and the way that shared social understandings can affect and influence the care that people receive. This was discussed in depth in Chapter Two, and certainly these earlier discussions are meaningful in the context of this study’s findings. However, as part of considering how existing fourth age discourse and shared social imaginaries can affect health care practice to the extent that failure to maintain could occur, I posit that it could also be useful to consider the figurative space that older patients, such as ALC patients living with dementia, are obliged to occupy once they become long term patients in the acute care setting. It is as if upon resolution of their acute care needs and upon their designation as ALC patients, that they enter an uncertain liminal space, a limbo characterized by waiting, where they are no longer acute care patients, yet utterly dependent on the services of an acute care setting that is not set up in a manner that benefits them or suits their needs.

### **9.3.2 Exploring Liminality and the ALC Experience**

Ethnographer Arnold van Gennep first discussed liminality in the early 1900’s, as part of

his work and study into ceremonial rites of passage (New World Encyclopedia, 2016; Purves & Suto, 2004). In the 1960's, anthropologist Victor Turner (1969) focused his work specifically on the liminal phase of van Gennep's rites of passage, describing liminality as an ambiguous and transitional space. As he explained, "liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial" (Turner, 1969, p. 95). Turner also connected liminality with being socially invisible (Leibing, Guberman & Wiles, 2016). This idea of being "betwixt and between" is evocative of the ALC experience, particularly in how the patients are designated as different than other hospital patients and requiring an *alternate* form of care, a somewhat ambiguous description of their needs as hospital patients that is "neither here or there".

#### **9.3.2.1 Pervasive liminality**

Extended hospitalization with an unknown end-date compounded by the challenges of dementia's symptoms and being cared for in an environment that is not well-suited to those living with dementia, likely further thrusts the person into liminality. As it has been stated, "Individuals in liminal spaces experience definitional ambiguity – they are no longer classified as what they were but are not yet classified as what they are becoming..." (Willson, 2019, p. 843). This seems to accurately sum up the waiting that characterizes the ALC patients' experiences, a time when they are no longer classified as acute care patients, but something in-between and an *alternate* type of patient. Certainly, hospitalized patients living with dementia have encountered liminality, where they have described feeling like "outsiders" in the hospital environment (Digby, Lee & Williams, 2018b).

While more traditional conceptualizations of liminality evoke a sense of possibility and of a change to come, liminality in the context of the ALC experience has quite different

implications, one of stagnation and possibly of decline, a pervasive liminality which was manifest in the patient participants' experience of long days without much to do and in their overall decline in health and wellbeing over time. Indeed, the concept of liminality has in some cases been portrayed as a static condition, rather than a process of transformation and "transition between two states of being" (Leibing et al., 2016. p. 12). Furthermore, one could argue that liminality within the dementia context certainly has connotations of decline and of not moving forward, particularly when considering the disorienting and challenging reality of living with a dementia diagnosis: the loss of memory, changes in functional abilities and the fact that dementia is an irreversible condition that continues to worsen over time. However, this is a very negative perspective of living with dementia, a common understanding of dementia that many have argued further marginalizes and stigmatizes people living with this condition (Innes & Manthorpe, 2012).

Nevertheless, there were aspects of the patient participants' experiences in hospital that were marginalizing or socially excluding and that likely were directly related to their dementia. This is particularly so when considering the participants' experiences of distress, understood and approached as "difficult behaviours" by ward staff, as well as the labeling of the patients as aggressive and difficult to care for. ALC patients, especially those living with dementia, can be considered at a disadvantage compared to other non-ALC patients. Certainly, the designation of ALC does "other" patients who inherit this label, who are no longer autonomous and able to return to their pre-hospitalization existence, and who are dependent on the acute care system to meet their daily care needs. These are important considerations when referring to the personhood and social citizenship perspectives that have been fundamental to this study. It is likely that the essential personhood of each patient, as well as aspects of social citizenship, in particular their

agency, are poorly recognized and supported as patients experiencing liminality. This also relates back to the earlier discussion on the passivity that characterizes their care and experiences in terms of the waiting they endure. As patients and individuals “othered” by their ALC status, they are not seen as partners or resources in their care (Bartlett & O’Connor, 2010), but rather patients whose bodies and needs require managing until more suitable arrangements for care can be made.

### **9.3.2.2 Liminality and other perspectives**

In terms of representations of liminality and dementia in other literature, Godwin & Poland (2015) discovered that individuals living with moderate to advanced dementia residing in care facilities experienced an ongoing sense of uncertainty and lack of clarity about their living environment, where residents experienced a liminal sense that “nothing was quite what it seemed” (p.239). This is certainly relatable to the patients’ experiences in this study, especially the uncertainty revolving around when they might be leaving the hospital setting. Birt, Poland, Csipke & Charleworth (2017) approached liminality in the dementia context from a sociological point of view. They explain that a diagnosis of dementia can create a state of liminality, or of ambiguity and uncertainty, and that existing social structures can limit people with living dementia from being able to move into a post-liminal state. They posit that a post-liminal state is possible for people living with dementia, and this successful transition occurs when an individual is acknowledged as a social citizen.

Other scholars have explored the concept of liminality in different contexts that clearly resonate with the ALC experience. For instance, Murphy, Scheer, Murphy & Mack (1988) utilized a liminal lens to examine physical disability in people with spinal injuries, whereupon they characterized the liminal state people found themselves in as something that “left them

socially ambivalent and ill-defined, condemned to a kind of seclusion” (p. 235). Purves & Suto (2004) examined the experience of hospitalized patients waiting for placement in discharge planning units, and used the concept of liminality to describe the waiting process as a state of limbo or a break in the patient’s personal narratives. More recently, Bruce et al. (2014) utilized a liminal framework to examine the experience of living with chronic and life-threatening illnesses. They found that people with long-term and life-threatening health conditions live with pervasive liminality or a constant in-between state that they called “wellness within illness, or living while dying” (Bruce et al., 2014, p. 42).

### **9.3.2.3 Negative implications of liminality**

All of these conceptualizations of liminality, while different in some ways, demonstrate that liminality is an experience common in various health contexts. These conceptualizations are also useful in examining and considering what ALC patients, particularly those living with dementia, are experiencing. As patients who are elderly and having to cope with dementia, along with the other challenges inherent in a long hospitalization, the liminality of their status likely heightens their vulnerability, increasing the risks that come with a lengthy stay in hospital. ALC patients living with dementia are not only marginalized by virtue of their dementia diagnosis, but also because of their designation as patients requiring an alternate level of care. Existing structures and processes in the hospital setting, particularly the labeling that is common to differentiate between type of patients, ensuring that they remain in-between, not a regular acute patient but different, does seem to perpetuate the sense that they are outsiders in the hospital setting. It could be argued that patients who are thrust into this in-between liminal space may not always have their needs recognized in ways that would benefit them. Nor is there much

opportunity for them to have their social citizenship recognized, or for them to exercise agency in meaningful ways.

The negative implications of liminality in the context of ALC patients living with dementia are numerous. As patients stuck in a liminal phase of waiting, there is a sense that everyone, not just the person and family members, but those tasked with providing care while in hospital, are waiting for the next stage in the patients' lives, whether that is transfer to facility or discharge home with enhanced services. There is focus on meeting their basic daily needs while they wait, but little to no focus on the active living that is important for people to feel connected to the world that they live in and that contributes to wellbeing. As described in the findings chapters, not much is happening for the patients from day to day, when one considers the dearth of activities and positive interactions that they are engaging in. Ironically, at the same time they are also experiencing much in terms of distress and upset, and deterioration in their health and functioning. Since my time as a transition nurse when I first became aware of ALC patients, and throughout the period of this research project, I have continued to question how it is acceptable that patients who are elderly and live with dementia have to stay in such an unsuitable care setting for so long, and experience poor outcomes as a result to their hospitalizations.

As mentioned previously, this relates to the attitudes and understandings of those participating in the patients' care that revolved around resignation and acceptance that patients' health and wellbeing would decline over time. Again, I believe the acceptance of the idea of "you don't use it, you lose it" directly affects care, and is more acceptable in patients experiencing liminality. On reflecting on the *Failure to Maintain* discussion earlier, I suspect that ALC patients living with dementia, are more likely to have their care needs rationed. While their care needs are no longer acute, they are still very complex. However, as patients

experiencing liminality whose care and time in hospital is ambiguous, seen as “alternate” and not fitting into the acute care setting, it becomes easier to ignore their needs. They simply are no longer seen as a priority, and as such, rationing of care is normalized and expected.

### **9.3.3 Unpacking the Behaviour Narrative**

Similarly, it seemed that nurses and other health care providers expected that patients would find their hospitalization distressing, and as a result they would manifest behaviours. I struggled throughout this research project with using the term “behaviour”, particularly as this relates to patients who were found to be or described as behaving poorly. Using the word behavior, usually in a negative way, seemed to imply that the patients were doing something wrong, and that they were to blame for the way that they were acting. It was a term that came up frequently in my field work, and I often witnessed patients “behaving” in ways that were challenging for staff and which directly affected the patients’ experiences. In fact, the challenges that the patients faced when it came to the way that they expressed themselves and how they behaved, were so significant that they warranted an entire chapter of findings. Overall, the behaviour narrative underlying the findings in this study as revealed in Chapter Seven, in particular the ease in which we label patients as behaving badly, is difficult to ignore and requires further exploration and consideration.

#### **9.3.3.1 Behavioural and psychological symptoms of dementia**

Behaviours are common for older adults living with dementia in hospital settings and are frequently understood as the behavioural and psychological symptoms of dementia (BPSD) (Hessler et al., 2018). BPSD was a term I heard several times from staff when they discussed how patients were behaving or reacting to their hospitalizations. Patients labeled as having BPSD often exhibit symptoms such as delusions, irritability, aggression and wandering (Hessler et al.,

2018), which were all “symptoms” that several of the patients in this study manifested. In many ways, BPSD is a biomedical term, where behaviours are understood as being directly related to disease and pathological changes in the brain (Yous, Ploeg, Kassalainen & Schindel-Martin, 2019; Dupuis, Wiersma & Loiselle, 2012). When the physician asked me for “science” to help with Mr. Chiang’s behaviours, I felt that this was reflective of a biomedical understanding of BPSD, where the patient’s behaviours “become things that need to be managed and controlled rather than understood” (Dupuis et al, 2012, p. 163). Certainly, this is reflective of the reductionist nature of the biomedical perspective. This is also where it becomes important to unpack common assumptions and understandings when it comes to BPSD and the behaviour narrative that is prevalent in our hospitals and care settings.

Often BPSD is seen as something that is negative, that needs to be reduced or fixed, and overall, reflects perspectives of dementia that are “deficit-oriented” (Woods & Buckwalter, 2018, p. 2) . The term BPSD first came into use in 1996 during an International Psychogeriatric Association meeting (IPA) (Cunningham, Macfarlane & Brodaty, 2019). It is important to note that the IPA meeting was sponsored by Janssen Pharmaceuticals, producers of the antipsychotic risperidone, a drug that is frequently used to treat patients living with dementia (Liebing, 2009). Since that time, the term BPSD has been widely accepted and used within various health care contexts. However, more recently there has been a push to reconsider BPSD terminology and associated dementia care practices and policies (Cunningham et al., 2019), which tend to pathologize behaviours rather than seek to understand the meaning behind them (Dupuis et al., 2012).

### **9.3.3.2 Responsive behaviours**

In fact, there is a growing movement to eliminate the use of the term BPSD, particularly

on social media where dementia advocates have started the #BanBPSD campaign (Cunningham et al., 2019). For instance, Kate Swaffer (2018), a well-known dementia advocate and scholar who is also a person living with dementia, has called BPSD a false construct that is stigmatising and that can lead to problematic approaches to care such as overuse of medications and restraints. Rather than BPSD, the term *responsive behaviour* is increasingly being used, where behaviours are understood as having meaning, specifically that the person is trying to intentionally communicate to others a concern or an unmet need (Clifford & Doody, 2018; Alzheimer Society of Ontario, 2017). As Dupuis et al. (2012) state:

A responsive behavior discourse views all actions as meaningful and moves us away from judging behaviors to *understanding meaning in actions* and responses. It means moving from a focus on dysfunction, deficit and decline, to recognizing, valuing and believing in the continued abilities of persons with dementia to express their experiences and act in purposeful, meaningful and even intentional ways (p. 170).

As such, responsive behaviours can be understood as the person trying to express themselves in some way, and this was evident in many of the interactions and situations that were described in the findings, particularly in Chapter Seven, where the patients were trying to express needs such as needing to go to the bathroom, not wanting to be touched, as well as wanting to be able to move about freely. Research has also demonstrated that people living with dementia may exhibit certain behaviours as a way of trying to gain a sense of control over an experience that is disruptive and hard for them to understand (Porock, Clissett, Harwood & Gladman, 2015). Staff who worked with the patients in this study often recognized or spoke of understanding that there was an unmet need that needed to be addressed. However, at other times, how patients “behaved” was interpreted as inconvenient, time-consuming and a barrier to

care. Nor did it always seem that staff recognized that the patients might be trying to express themselves in a meaningful or intentional manner. Unfortunately, it seemed that the way a patient was “behaving” was often attributed to their diagnosis of dementia, and efforts to understand what a patient was experiencing or feeling were not always undertaken.

### **9.3.3.3 Stigma and behaviours**

The stigmatizing nature of the behaviour narrative also needs to be further explored, particularly in light of the fact that stigma continues to be a significant issue for people living with dementia (Swaffer, 2014). While I was struck by the way family members were made to feel badly about the way that their relative was acting out, I was very much taken aback by Mr. Hasting’s personal feelings regarding the purple aggression sign by his bedside. Initially, I was surprised that he was aware of the implications of the sign, and how he felt that it unfairly categorized him. I then realized that I was surprised by his understanding because I assumed he would not be aware of what the sign signified because of his dementia diagnosis. This was an unfair assumption on my part, where I had fallen prey to the “decline” narrative commonly associated with understandings of dementia and the people living with this condition. This learning experience also clarified for me how easily we label patients in health care contexts, and as part of that, do not carefully think about how the labels can personally affect the individuals that we “affix” them to. It was a good reminder of how easily a diagnosis of dementia can become what Doyle and Rubinstein (2014) call a “master status”, where the label or classification of dementia can affect individuals’ social experiences, negating all other identities they might have. The master status of dementia can also cause others to interpret “normal” behaviours as symptoms of dementia, such as when people are walking about but are labeled as “wanderers” (Doyle & Rubinstein, 2014; Brittain, Degnen, Gibson, Dickinson & Robinson,

2017), and lead to easily making assumptions about people's abilities.

Behaviours, especially aggression, can directly impact caregivers who can experience burnout and physical harm (Herron & Wrathall, 2018). I am not disregarding the genuine concern that nurses and other staff felt when I overheard them saying "don't hit" or "don't kick" when providing care for patients who were reacting and expressing themselves physically. Nor am I discounting the real harm that caregivers experience when they are on the receiving end of physical aggression. As described earlier, Mrs. Ho at one point did bite one of the nurses, and this must have been a difficult experience for that person. However, from the patient's perspective, being viewed and deemed as aggressive, difficult to care for or violent can negatively affect that person's sense of self, as well as the quality of the care they receive (Herron & Wrathall, 2018; Dupuis et al., 2012). When focus becomes directed on managing the "difficult behaviours", especially with chemical or physical restraints, further barriers for meaningful participation in daily life are put in place (Mitchell, Dupuis, Kontos, Jonas-Simpson & Gray, 2020).

Consider the experiences of Mr. Chiang, whose behaviours became untenable to staff, leading to being medicated, which in turn caused significant sedation. From a social citizenship perspective, he certainly was not an active participant in the world around him when he slept heavily in his chair in the hallway for hours at a time after being sedated. The lack of agency and active involvement in daily activities experienced by patients like Mr. Chiang reveal that their social citizenship is poorly recognized and supported. This perspective also brings attention to the tendency for society and systems of care to neglect the "universal rights and entitlements" of those living with dementia, focusing rather on the issues and concerns that are problematic and in doing so, locating "them on the margins" (Milne, 2010, p. 231). In many ways, Mr. Chiang, and

other patients with similar experiences, were figuratively and literally relegated to the margins of the hospital unit, especially as they spent time sitting or sleeping in Broda chairs in hallways and by nursing stations.

#### **9.3.3.4 Behaviours, restraints and labeling**

Mitchell et al. (2020) ponder what they call “the dehumanising patterns seen in dementia discourse and practices” (p. 3), attributing much of it to the strength of the biomedical model, and the language that is entrenched in this perspective. This is why it is so easy to label patients as aggressive, without thinking of the greater implications to the persons whom nurses and other health care providers are caring for when this occurs. This is likely why it is generally accepted practice to restrain patients who are otherwise mobile in chairs, what Dewing (2001) calls *restrictive management* in nursing practice. Use of restraints is more prevalent in hospitals for patients with cognitive impairments (Innes, Kelly, Scerri & Abela, 2016; Iecovich & Rabin, 2014), and is often justified as a measure taken to ensure staff and patient safety (Moyle, Borbasi, Wallis, Olorenshaw & Gracia, 2010). Unfortunately, use of restraints in hospitals continues to be common when it comes to managing older patients, despite evidence showing that physical and chemical restraints are detrimental to people’s wellbeing (Yamamoto & Oso, 2009). It is also important to note that inappropriate use of antipsychotic medications is common for adults living with dementia. A recent Canadian retrospective cross-sectional study (Rios et al., 2017) examining clinical data across health care sectors found that antipsychotic use was highest for ALC patients living with dementia (54%) compared to other areas such as home care (26%) and long-term care (48%).

In addition, there is a tendency in health care toward utilizing surveillance methods and managing chaotic bodies where “practitioners are charged with the mandate to create docile

‘dementing bodies’ through rigorous and continuous bodywork or policing to maintain and marshal bodies...” (Kontos & Martin, 2013, p. 292). Certainly, in the context of this research, this involved some type of medicated or physical restraint, signs on patients’ doors indicating that they were aggressive, and placing people who were exhibiting problematic behaviours in locations where they could be easily monitored and controlled.

According to the literature, nurses may not always “see” the person behind the labeled dementia condition (Digby et al., 2017), only the problematic symptoms. When we label people, particularly as different from others and as difficult to care for, it can distance us from acknowledging the person behind the behaviour or the label, and instead maintain focus on the body, and the problematic aspects of the corporeal form. It could be argued that the label or designation of ALC could be hard to see beyond as well, particularly in the context of this study. Unfortunately, part of the cultural norm in the hospital setting is to label patients living with dementia which not only serves to homogenize them as all the same despite differences in backgrounds and personal experiences, but also paradoxically categorizes them as being different from other patients (Cowdell, 2010a). This was evident in the experiences of the patients in this study. It was clear that each person was very different in his or her own way, yet there were many similarities in the way that they were treated.

Nevertheless, when we critically consider what it really means to restrain people and hold them in place because of the way they are behaving, how is this defensible? How do we justify this? Again, I ask these questions knowing that restraints are used because staff likely see no other options, are concerned about patient safety as well as their own, and feel that they could not get their work done otherwise. In this sense, use of restraints could be deemed an acceptable practice, an unfortunate but necessary intervention. However, it is worth thinking about what

happens when we focus on the pathology, the disease, without considering the greater context of the person. From a personhood lens, it can be dehumanizing to only treat the symptoms, without considering what the behaviour might be indicating about the person, or what they may be trying to tell us by the way they are acting. As Hughes (2014) states, “our understanding, therefore, of people with dementia must be broadly based” (p. 1412). Hughes has written extensively on what he refers to as the aesthetic approach to dementia care, where meaningful connections are made with patients by accounting for and being open to each person’s context and manner of being in the world (Hughes, 2013, 2014). Accordingly, this broader approach and perspective in dementia care “is a matter of aesthetic judgement as much as it is a scientific, pharmacological, cognitive, psychological or social endeavour” (Hughes, 2013, p. 356).

In addition, we further dehumanize the people we care for when we use language like “placing” a person in a care home, as if they are an object to situate and put aside. Dehumanizing language is pervasive in our systems of care, and generally accepted as the norm. Unpacking the reasons for this is a complex undertaking, likely related to the complicated system that is the acute care setting, and the ageist perspectives and understandings that are widely accepted in society and in health care. However, when considering the tendency to label and treat patients a certain way, it does raise questions as to whether patients, such as ALC patients living with dementia, may be seen as less worthy than others. Certainly, scholars have explored this idea, that more complex patients such as those living with dementia, especially those who present with behaviours that are disruptive to the routine of the hospital setting, can be labeled as “unworthy” (Digby, Lee & Williams, 2018a). Overall, when we label people with ease, there is the risk of disregarding their worth as persons and in doing so, we can socially malign them in accordance with Kitwood’s (1997) perspective on personhood. It is also useful to reflect on Kitwood’s

definition of personhood here, and we can see how personhood can be *un*-bestowed in health care contexts like the hospital setting, when powerful labels and common care practices can erode patients' essential personhood and sense of self.

### **9.3.4 Looking Beyond Labels**

The thematic explorations in the final chapter of findings powerfully remind us of the importance of countering “unworthy patient” narratives, as well as challenging the ease in which we label people. Despite the difficult circumstances that they found themselves in where it could be hard for others to see beyond the disposition of patient-hood, the individuality, resilience and agency that the patient participants consistently demonstrated and embodied was illuminating and inspiring. It can be easy to forget that a patient is a distinct individual, especially in an institutionalized setting like the hospital, when there is a dementia diagnosis, and when responsive behaviours are common and expected. For liminal individuals such as ALC patients, who are already categorized by virtue of their designation, further labeling such as “aggressive”, “noisy”, uncooperative” and “difficult to place” adds to the stigma they must deal with. It likely puts these patients at higher risk of not having their needs fully recognized or addressed, and as discussed earlier, makes it easier for the phenomenon of *Failure to Maintain* to occur. This highlights the importance and necessity of person-centered approaches to care, where value is placed on the distinct personhood of each patient (Tay et al., 2018).

#### **9.3.4.1 Where does person-centered care come in?**

Person-centered care has been defined as “behavior that acknowledges the subjective experience of the individual; involves sharing decisions and offering choices; uses an individual’s life story to guide their care; and focuses on the person’s retained skills and abilities” (Blake, Berry & Brown, 2020, p. 427). Rather than focusing solely on completing

tasks, this care approach prioritizes the relationship with the person (Clissett et al., 2013), and is based on the principle that each person is unique and as such, the care provided should be planned with each individual's needs, strengths and interests in mind (Fazio, 2013). Lusk and Fater (2013) completed a concept-analysis of person-centered care from a nursing perspective, and determined that it should include individualized patient care, a caring attitude and encouraging patients' autonomy. Person-centered care practices have been shown to improve outcomes for patients such as decreasing length of stay in hospital and increasing patient satisfaction (Isaac, Buggy, Sharma, Karberis & Maddock, 2018). This approach to care for people living with dementia has been recognized internationally as best-practice (Surr, Smith, Crossland & Robins, 2015), and owes much to the work of Kitwood and other scholars who first brought attention to the importance of recognizing and supporting the personhood of people living with dementia.

Unfortunately, the provision of person-centered care is challenging in a hospital setting (Clissett et al., 2013; Rushton & Edvardsson, 2018; Tay et al., 2018), and nurses commonly report difficulties in incorporating person-centered strategies in their practice (O'Rourke, Thompson & McMillan, 2019). This has been attributed to the fast-paced nature of hospital units, where staff may not feel that they have time to engage in person-centered care practices (Tay et al., 2018). In addition, acute care staff may not be well prepared or understand how best to implement person-centered care (Røsvik & Rokstad, 2020), and organizational factors, such as the importance of meeting productivity and financial objectives, can take precedence over care practices that can take time and effort (Clissett et al., 2013).

Specific care approaches developed to facilitate person-centered care for people living with dementia have been developed over the years. For example, the P.I.E.C.E.S framework,

developed in the late nineties in Ontario, is a holistic approach that takes into account the person's beliefs, personal background and culture, and is focused on responding to and preventing responsive behaviours (Yous, Ploeg, Kaasalainen & Schindel Martin, 2019). Similarly, Gentle Persuasive Approach (GPA) is person-centered and considers the physical, interpersonal, environmental and social factors that can lead to people expressing unmet needs (Schindel Martin et al., 2016). These approaches have been shown to be promising in improving dementia care and meeting people's needs in the acute care setting (Schindel Martin et al., 2016; Yous et al., 2019). However, specialized training is required for these specific care frameworks, as well as sustained commitment from leadership for continued education and training.

#### **9.3.4.2 Impact of “the basics”**

Approaches and frameworks such as P.I.E.C.E.S and GPA are likely worth investing in, especially as health care workers, including nurses, consistently report that they feel unprepared and undertrained to care for patients living with dementia (Digby et al., 2017). Ensuring that the hospital and unit environment itself is dementia-friendly also has significant benefits for patients. This would include fostering and creating environments where patients can easily orient themselves, and where they can take part in meaningful activities (Brooke & Semlyen, 2017; Eastham & Cox, 2017). Importantly, research has shown that patients want to feel emotionally safe, valued and “treated as someone who mattered” (Hung et al., 2017, p. 7). This is an important reminder that attending to the basics or attention to the “little things” (Hung et al., 2017, p.1) really seems to make a difference for people.

In accordance with this idea of the little things mattering, the findings that I want to highlight here relate to the impact of simple acts of caring, and the import of attention to basic bodily functions. When I asked them what good care was, the patients consistently reported that

it really made a difference when they were comfortable and had basic and simple needs attended to. For a few of the participants, having a regular bowel movement was very important. Conversely, patients encountered challenges when basic but critical needs, such as regular bowel movements and being able to void, were not effectively dealt with. In addition, it really seemed to make a difference when nurses and other staff took a few moments to connect to patients before providing care, whether that was taking the time to say hello or giving the patient a few moments to orient themselves. This seemed to show the patients that they mattered as people, that they were worth the effort of taking just a little extra time to talk to and explain what was happening.

This is a good reminder of the impact that basic nursing care can have, particularly care that is responsive to each person's particular needs. Certainly, it demonstrates that relational approaches to care matter and can make a difference. Along this line of thinking, it is also imperative for nurses to listen to the patients they care for, to what people are telling them or trying to communicate to them. Many of the patients in the study did not feel listened to on a regular basis, and this is something that should be a critical take away from this work: that nurses need to listen to the people they are tasked with providing care to.

#### **9.4 Implications for Practice**

While this study is focused on the patients' experiences and perspectives, I would like to shift the discussion at this point to consider implications for nursing practice in the context of what we have learned from the patients. Nurses need to come to terms with their role in contributing to the care experiences of patients, particularly in regards to the issues and concerns that have been discussed in this chapter so far. Specifically, nurses need to consider how to

ensure that patients do not have to struggle with pervasive liminality and not fitting into the hospital setting. As a nurse, I do not think that we can currently justify the care that we provide within a system where it is accepted that older adults will decline and not thrive within our care, where they will become agitated and regularly distressed, and where they will be labeled certain ways. Nurses are one of the largest groups of health care professionals, particularly in settings such as acute care. We play a role in furthering practices that are unhelpful and potentially damaging for patients by not acknowledging or taking actions to rectify these concerns. We also have the potential to contribute to significant, impactful and lasting change.

When I think about the personhood and social citizenship perspectives that formed the theoretical scaffolding around which I built and approached this study, I cannot help but return to these points of view in considering implications for nursing practice. To reiterate, a personhood approach to dementia care involves challenging understandings and practices that de-personalize the person living with dementia, and it “implies recognition, respect and trust” (Kitwood, 1997, p. 8). Reflecting on what we have learned from the patient participants, it did not seem that they always trusted the nurses who cared for them, as they often exhibited fear and distress when receiving care. Certainly, nurses and other care providers did not always trust the patients in return, as they were afraid of being hit or kicked at when providing care. I am also unsure about whether the patients were always recognized and respected as whole persons, as it was difficult for nurses to see beyond patient-hood, ALC designation and the dementia diagnosis.

As discussed previously, social citizenship revolves around the rights of people living with dementia, who as active citizens in society should not experience discrimination because of their diagnosis and should have the opportunity to experience and participate in life as fully as possible (Bartlett & O’Connor, 2010). It did not seem that the patient participants in this study

were encouraged to actively participate in the daily unfolding of their lives during their time as ALC patients. While some may argue that they should not be expected to actively participate in daily life because of their dementia diagnosis, findings in this study demonstrate that this is not the case. The patients, even those living with very advanced dementia, consistently expressed themselves as individuals with distinct needs and wants, and demonstrated agency and resiliency despite the challenging situation they found themselves in. However, their ability to do this was not always recognized, nor was it encouraged.

#### **9.4.1 Acknowledge, foster and sustain ability**

This brings us to the role nurses in hospitals can play in acknowledging, fostering and sustaining the personhood and social citizenship of the people they are caring for. This in particular relates to the importance of person-centered care and the need to actively involve patients in their care and daily hospital life whenever possible. This study has reinforced the idea that attention to the basics and the “little things” do make a positive impact for patients, and have highlighted the negative consequences that can occur when effort to take the time to be attentive to these aspects of care are not undertaken.

For some patients, acknowledging, fostering and sustaining personhood and social citizenship might include involving them in planning and decision making, when appropriate. For others, this might include more basic but still vital interactions such as taking the time to communicate with the person, asking their opinion about something, and giving them a few extra moments to take in and parse what is happening to and around them. These types of interactions may seem straightforward and simple, but they are fundamental and crucial, and when undertaken made a difference for the patients in this study. In fact, person-centered care is

complex in nature, takes effort and time, requires a holistic outlook and mutual respect, and a sharing of power and responsibility (O'Rourke et al., 2019).

Despite these complexities, as O'Rourke et al. (2019) state, "the nurse has a moral obligation to incorporate these attributes and behaviours into their nursing practice" (p. 4). Here is where individualized nursing care plans that are person-centered and focused come into play, where specific information relating to each person's needs, abilities and preferences can help to shape care practices. Several of the nurses that I spoke to referred to the importance of care planning, but there also seemed to be some indication that care plans might not always be completed or properly used. Person-focused care plans can also detail the "little things" that make a difference to patients, as well as the vital strategies and interventions that can help patients feel that the basics that matter to them are addressed in a way that suit each person.

Recognizing that a person's sense of self, and how they express themselves, can be embodied is important for supporting the personhood and social citizenship of patients, especially for individuals who might be experiencing significant challenges with cognition and communication. Embodiment studies have contributed importantly to dementia care, particularly in the way they have challenged more common biomedical perspectives of dementia that are reductionist in nature (Hughes, 2001; Kontos & Martin, 2013). As Pia Kontos (2004) explains, a person's selfhood exists in the body (corporeality) rather than only in cognition. By paying attention to a person's bodily and natural movements and "propensities", one can begin to see how a person's selfhood, and distinctiveness, can be exhibited despite changes in cognition (Kontos, 2004). This perspective attributes agency to a person's body in expressing selfhood via one's bodily movements, gestures and habits (Kontos, 2004, 2005). Recognizing the embodiment of others' selves can be challenging, especially in the fast-paced and ever-changing

hospital setting where staff may not feel that they have the time or opportunity to respond to patients in this way. Nevertheless, it can be argued that “embodiment should be at the ‘heart’ of person-centred nursing practice” (Draper, 2014, p. 2238).

Furthermore, in recalling Mrs. Rogers’ words that staff *should* make the time to listen to patients, a similar argument could be made for taking the time to recognize and respond to the embodied individuality and personhood of ALC patients living with dementia. This would involve conversations with family members whenever possible to understand how patients tend to express themselves and their needs. More importantly, this should also include conversations and interactions with patients to determine and understand distinct aspects about them, which could be indicated in care plans and help to facilitate care interactions and meet their needs.

I cannot discuss sustaining and fostering personhood and social citizenship without bringing up the consequences of functional decline. How can we support people as whole human beings, when their health and wellbeing decline and worsen as a result of their hospitalization? The physical and emotional decline that the patients experienced in this study has several critical implications for practice. Patients need to be able to move their bodies, to whatever extent their bodies allow them to. Mobility and movement, similar to other bodily functions discussed so far, is a basic need that requires attending to. Not every person will be able to walk around, but that does not mean that they must be immobilized or restrained in one place. A few of the nurses in this study talked about the efforts that they made to ensure that patients were able to walk and mobilize regularly. This type of effort should be standard practice. Post-surgical patients are mobilized as soon as possible to prevent post-operative complications. ALC patients forced to wait long-term in hospital should be given similar consideration, in the sense that their bodies need to remain active.

In addition, nurses must consider the negative implications of the behaviour narrative prevalent in our hospitals. Part of acknowledging, fostering and sustaining ability also revolves around recognizing that people living with dementia are likely expressing themselves, communicating an unmet need or dealing with a fundamental concern that requires attention. We need to realize that the manner in which we treat patients living with dementia, if done poorly, likely contributes to or worsens problematic behaviours. In considering that we may be failing to maintain the physical health of our patients, we must also take into account how our current practices are also failing to maintain their emotional and psychological wellbeing.

As one of the nurse participants stated, the practices that have been discussed above are not “rocket science”, meaning that they are not revolutionary and many of these recommendations relate to basic nursing care and approaches. However, I state this knowing that making changes, even simple ones, can be difficult, particularly when considering the complexities and issues that exist within busy hospital systems. Nevertheless, nurses as a collective entity have the power to make significant improvements to the care that patients receive, and even small changes in practice can lead to meaningful change over time.

#### **9.4.2 Challenge common practices and understandings**

Nurses need to be reflexive in their practice, and pay attention to the language and the labeling that is inherent in regular nursing care and that “other” and disenfranchise patients. Nurses also need to be able to carefully consider what it means when patients living with dementia are “behaving” a certain way, and avoid jumping to conclusions that “behaviours” are simply a symptom of the disease. Inherent in this is the critical examination of restraint use, and considering options and approaches to care that do not automatically resort to physical and chemical restraints. Nurses should also reflect on the embodied nature of others, and in particular

how patients as individuals in their own right share aspects of themselves and their needs via their bodies and in embodied ways.

Nursing has long upheld that it has a specialized service to offer to the general public, specifically in the provision of individualized, person-centered and holistic care to those they care for (Maben et al., 2007). Furthermore, nursing's mandate is that it has a "professional and ethical commitment to promoting the health and well-being of patients" (Rodney et al., 2013, p. 166). There are values and ideals that are the foundation of many training and education programs (Maben et al., 2007), and are a part of the nursing code of ethics (Canadian Nurses Association, 2007). From this perspective, it is hard to understand how a culture of devaluing patients living with dementia could emerge, whereby we might be failing to maintain our patients' health and wellbeing. Research demonstrates that a certain habitus of practice can develop once nurses are socialized into a particular practice setting, and that many of the core principles we are taught in nursing programs can be set aside when faced with the realities of practice (Nairn, Chambers, Thompson, McGarry & Chambers, 2012).

New nurses may come out of training prepared to provide holistic and person-centered care. However, nursing ideals and expectations may have to be adjusted and lowered over time, with repeated exposure to the practice setting (Maben et al., 2007). The hospital is a complex care environment, in and of itself a structure within the social world. As such, a particular habitus of practice is expected within this social location. It is likely nurses learn to "nurse" a certain way based on the structures, understandings and expectations prevalent within the acute care setting, despite training that may have taught them otherwise. Thus, common practices such as focusing on task-based approaches that are not necessarily person-centered but meet the demands of the setting, could prevail. Research has shown that habitus is entrenched, where

existing practice is accepted “as the way things are” (Cowdell, 2010b, p. 47) and new staff are quickly socialized into the existing culture of care (Cowdell, 2010b).

Relational practice was discussed earlier as an important part of my disciplinary grounding. The way that I navigated the relational space while undertaking data collection, particularly in how I endeavoured to create an *I-Thou* space whenever possible, was critical in facilitating comfortable and empowering interactions with the participants. Relational practice also has relevance in considering implications of the study findings for nursing practice and the care of ALC patients living with dementia, particularly when discussing how nurses can challenge common practices and understandings. Often relational practice is understood solely from an interpersonal perspective in terms of the nurse-patient relationship, without consideration of the greater contexts that can affect relational processes (Hartrick Doane, 2014). However, as Hartrick Doane (2014) states, “we need to more consciously consider how meaning, intersubjectivity, and context are integrally related and how broader ideologies, norms and discourses shape and influence relational action” (p. 85).

As Rodney et al. (2013) state, “nurses are constrained by the structures in which they operate, yet we also need to recognize nurses’ own roles in (paradoxically) perpetuating the very structures that constrain them as moral agents” (p. 167). Challenging common practices or the ways that “things are usually done” is not an easy undertaking, but it is necessary. While nurses might feel uncomfortable and unhappy with the care they are providing (Tadd et al., 2011), simply accepting how things stand does not do much to improve the situation. Thus, it is vital for nurses to consider how social understandings and ingrained practices could impact patient care and relational practice, and to find ways to challenge them. This might include recognizing that

they do not possess enough knowledge to care for complex patients such as ALC patients living with dementia, and requesting education and training.

This type of request may not always be supported by leadership, or there might not always be opportunities for formal training. However, even small changes in thinking and approaches to care could make a difference, such as challenging the idea that certain patients do not fit into the hospital setting. Rather, all patients in acute care, whether they are designated ALC or not, deserve the same considerations and care practices. Also, our care approaches need to reflect the demographics of this current era. Patients in general are older and will be more complex, living with conditions such as dementia. In addition, we cannot expect that there ever will be a “perfect” patient who fits in perfectly in our system of care. As nurses we need to realize that without challenging the status quo, change is unlikely to occur and hospitals could “remain potentially harmful places for people with dementia” (Clisset et al., 2013, p. 1502). I contend that this is unacceptable and that we can do better.

#### **9.4.3 Recognize ALC as a significant transition**

There are implications for health care leaders, in terms of investing in education and training for hospital staff, such as P.I.E.C.E.S and GPA, that will help nurses and other health care professionals understand person-centered approaches and shift the focus from problematic to responsive behaviours. However, from a front-line perspective, what can ward nurses and nurse educators do to improve the care of ALC patients living with dementia? Is there a way to re-imagine care that acknowledges and brings to the fore their needs as health care users, where priority can be placed on maintaining and fostering their health? It could be argued that ALC designation and the subsequent hospitalization period as an ALC patient is a significant transitional period for the patients, and this could be one place to start.

Certainly, ALC patients experience a myriad of transitions throughout their hospitalizations, such as their transition from acute to ALC patient, to anticipating the transition from hospital patient to resident in a long-term care facility. They also, as previously described, experience transitions in their health care status throughout their hospital stays. Overall, there is a transitional trajectory in terms of what happens for them once they are designated ALC, in the sense that they do transition on from the hospital, and experience a variety of changes from the date of ALC designation to that of eventual discharge. Nevertheless, when considering the “waiting around” that characterizes an ALC hospitalization, and the differences in care that ALC patients experience compared to non-ALC patients, such as no longer receiving regular rehabilitation services, it seems that their time as ALC patients is not recognized as a significant transition in their lives, particularly from a health care and nursing perspective.

This is a significant gap, as the concept of transitions has been extensively explored in health care literature, particularly in the field of nursing, and is a useful lens from which to consider the changes that people can experience during transitional periods in their lives. It has been recognized that people can experience different types of transitions throughout their lifetimes such as developmental, organizational, situational and health/illness transitions (Geary & Schumacher, 2012). From a nursing perspective, Meleis and colleagues have developed and researched what they call Transition Theory (Schumacher & Meleis, 1994; Meleis, Sawyer, Im, Hilfinger Messias & Schumacher, 2000; Meleis, 2010). Transition Theory is focused on the nature of the transition occurring, the conditions that facilitate or inhibit it, the types or patterns of responses occurring, and where nursing can make an impact in assessing a person’s readiness and preparedness for transition (Im, 2011; Joly, 2016).

Overall, Transition Theory considers the health challenges that individuals experience during major transitions in their lives, and takes into account the positive impact nurses can have during these periods of change (Bohner, 2017). From a scholarly and nursing perspective, transitions have been considered in a variety of contexts: from patients' transitions from intensive care units (Haggström, Asplund & Kristiansen, 2012), transitions from hospital to home (Allen, Hutchinson, Brown & Livingston, 2020), to the transitions that young people with complex medical issues experience as they move into adulthood (Joly, 2016). Transitions have also been explored with older adults, and it is important to note that older adults can experience unfavourable outcomes when care transitions are poorly managed (Mitchell et al., 2018; Allen et al., 2020).

I discuss transitions in the context of this work, not to focus specifically on Transition Theory, or other scholarly work in the field of transitions. Rather my intent is to highlight the active nature of health care practices and approaches that focus on transitions, and the recognition that individuals can experience significant changes during health care experiences. Furthermore, health care professionals such as nurses can positively influence people's experiences and health outcomes during these times. Acknowledging and addressing the considerable transitions that ALC patients living with dementia are experiencing could be a more positive and active way to recognize and meet the needs of patients as they wait. It could also be a way to define what "ALC" care is. This could help to move the focus of "ALC" care away from the passive waiting that characterizes it.

More specifically, approaches to care for ALC patients informed by a transition lens could involve care planning that sets goals of care from the onset of designation, preferably with the input of the patients, as well as from family members when appropriate. This would include

identifying and capitalizing on patient strengths, as well as recognizing possible risks and vulnerabilities, such as potential for functional decline and responsive behaviours, and proactively planning on how to prevent and address them during this time of transition. The goal would be to facilitate and maintain health and wellbeing, whatever that would mean for each patient. Care planning that acknowledges the significant transitions that ALC patients living with dementia experience and that involves them in their care as much as possible could help to resolve the liminality that they experience. While patients would continue to wait, this waiting could be done in a way that facilitates movement to the post-liminal state that Birt et al. (2017) posit, as social citizens deserving of appropriate and transitioned-focused care.

## **9.5 Other Recommendations**

In this section, I build on the previous discussion of implications for practice and identify specific recommendations for health policy, nursing education, as well as future research.

### **9.5.1 Health policy**

While it was not the purpose of this research to focus on health policy, given that it was an ID study aimed on developing knowledge for nursing practice, there are significant policy implications that stem from the study's findings. These implications warrant discussion and consideration, particularly when contemplating how the findings from this research could pave the way for health care policies that recognize and promote the health care needs and rights of ALC patients living with dementia.

In particular, policy around the use of restraints for these patients should be examined. The setting where this research took place does have policy guidelines when it comes to the use

of restraints in the acute care setting. This includes a policy of Least Restraint<sup>10</sup> for all patients, meaning that patients have the right to freedom of movement, should be able to interact with others in their environment, and have their autonomy supported as much as possible. However, according to the policy, restraints are permissible when patients' actions or behaviours could result in harm to others or to self, and other interventions have been first explored. Despite these caveats, this research has highlighted the ease in which older patients with complex needs are restrained in acute care, demonstrating the need for critical examination of existing Least Restraint policy, especially for older and complex patients who stay long periods of time in the hospital. Overall, policy analysis regarding use of restraints for patients living with dementia is recommended, and should focus on the use of Broda chairs as restraining devices for this population of patients, as well as the use of sedating medications to manage responsive behaviours.

In regards to other policy implications stemming from this study, future policies should focus on care strategies and initiatives aimed at protecting abilities and preventing decline for older patients living with dementia in the acute care setting. It should not be an expected aspect of hospitalization that patients will decline significantly in their physical and emotional health and wellbeing. In addition, many of the policy documents that were included in the literature review of this dissertation were written by physicians, as well as policy specialists who are not nurses. Nurses have real-world experience in the care needs of patients, and have important knowledge and experience to share as a result. As such, nurses need to be regularly involved in the development of health policies in general. Certainly, from the perspective of this study, future policies directed at improving the care of ALC patients living with dementia would benefit

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<sup>10</sup> I have not cited this policy as doing so would reveal the Health Authority where this research took place.

from the input of nurses. As the health care professionals who tend to spend the most time with ALC patients, nurses have real-world knowledge and experiences to share that could contribute to better understandings on how hospital care for these patients could be improved. In addition, the perspectives and subjective experiences of patients themselves should be the basis on which policy is developed.

### **9.5.2 Nursing education**

Ongoing education for nurses, for both front-line nurses and those in leadership, is needed to support greater understanding of and engagement with person-centered care practices, particularly in regards to how best to support patients living with dementia. While personhood and social citizenship frameworks are prevalent in dementia-specific literature and in programs of care such as P.I.E.C.E.S and GPA, undergraduate nursing education could benefit from having these theoretical perspectives more deeply embedded in curricula, and not just in gerontological nursing courses. The concept of social citizenship in particular has important implications for countering the hegemony that is inherent in much of our health care system, in reminding nurses in training that all patients have rights, in countering the “do for” mentality that is common in nursing, and in promoting a space where patients can advocate for themselves in an increasingly inequitable and challenging world.

### **9.5.3 Future research**

Nursing-focused research is an avenue in which useful knowledge can be developed and later used for policy development. Encouragingly, there is much activity occurring in terms of nursing-led research devoted to improving dementia care and understanding. Increasingly, nurse researchers are also working to include people living with dementia directly in the research process. While this study was guided by a specific disciplinary perspective, future research that

has a broader standpoint could be useful. Research informed by critical theory and frameworks could provide important insight into the hierarchies and engrained power structures that likely strongly influence care practices and experiences, and in doing so could provide important insights into larger system issues. Similarly, research into older adults' hospital experiences could be approached with a lens of precarity. As Grenier et al. (2017) explain, "to be precarious is to be at risk, or vulnerable, in some way" (p.10). Certainly, vulnerability is a characteristic often associated with people living with dementia, as well as with the aged, and it was clear that the patients in this study, as elderly persons living with dementia, were vulnerable to deteriorations in their physical health and emotional wellbeing as time went on.

As human beings, we are all vulnerable to a certain extent, more so at some times in our lives than others. In addition, certain groups of people can also be more at risk for being vulnerable, and in this sense precarity is "inherently shared, but unequally experienced" (Grenier, Lloyd & Phillipson, 2017, p. 323). Thus, there is more to considerations of precarity than simply acknowledging that some people, because of certain health conditions or times in their lives, are more vulnerable or at risk than others. There are also the social factors and understandings, as well as structures and practices that are in place that can play a major role in contributing to the precariousness of a person's situation (Fine, 2020).

Precarity in scholarly literature is often discussed as it relates to the structures in society that contribute to the inequities, hardships and distress that certain people can experience (Grenier et al, 2017). Certainly, there is relevance in discussing precarity in the context of older adult and dementia care, especially when taking into account existing fourth age discourse and the social imaginary of dementia, and how these social understandings and perspectives could inform and affect the kind of care that patients in hospital can receive, as well as how these

understandings can thrust people such as ALC patients living with dementia into liminality. Utilizing a lens of precarity in which to consider the ALC experience could help to understand how patients are positioned within a health care system that is supposed to provide care for them, but does not really meet their needs.

This study has demonstrated that liminal and difficult to access experiences and perspectives can be successfully uncovered and brought to the fore. People living with dementia have important information, understandings, perspectives and experiences to share with others, especially with those who work within existing health care systems and are responsible for providing quality care for them. Accordingly, this study shows that our older citizens, who can often be marginalized and stigmatized because of their age and the trappings that often accompany later life, are a valuable source of knowledge. As mentioned, continued involvement of older people living with dementia in research is needed, especially as this population of citizens will increasingly require health care services in the coming years. The necessity of continuing to access the experiences of older people takes on additional significance at this juncture in time, when globally we are experiencing a pandemic that is revealing deep inequities in society. Unfortunately, the ageism that has been laid bare and the ravages of COVID-19 on the population of older Canadians in our long-term care system are impossible to ignore, exposing the work that needs to be done to ensure that older people can expect to receive safe and appropriate care, wherever they may find themselves.

## **9.6 Study Limitations and Strengths**

As with any work, there are limitations to this research study that must be discussed and considered. Similarly, there are aspects that worked out well and contributed to the strength of

this dissertation. While I address the complexities that come with conducting research with participants for whom English is a second language, I do not focus on the cultural aspects and understandings that likely influenced and affected the patient participants' experiences. Several of the patient participants were of Asian descent, and their cultural backgrounds were not explored in this study, which is a potential limitation. A deeper consideration of cultural factors and how they might have affected the patients' experiences would have been interesting and important, and would have fit in well with the personhood and social citizenship orientation of this research.

I would have also liked to have recruited patient participants more evenly across the three units that I spent time on. Six out of eight patient participants were on the same unit (Stroke/Sub-Acute), and I was only able to spend time with one patient on each of the other two units (General Medicine and the ACE unit). It would have been interesting and possibly quite illuminating to spend more time on the units where I recruited fewer patient participants. This is because the culture of care might have been quite different on these units, and having not been able to spend as much time on them, I was not able to pick up on any substantive differences in terms of the patients' experiences on these wards. However, as mentioned previously, there did seem to be more ALC patients on the Stroke/Sub-Acute unit during the time that I was at the study site, and the pattern of recruitment that subsequently occurred reflects this. The PCC on this unit was also quite engaged in the project and eager to help with recruitment, which could also account for the success in recruitment in this particular location. This is where recruiting solely via the PCCs could have been a limitation of this study, and in hindsight had I posted recruitment posters, I might have recruited more participants on the other units.

Overall, I do not think that I could have recruited in substantially different ways, and the

manner in which recruitment occurred reflects the vagaries and fortunes of research, in that there are often aspects of the research process that are difficult to control. Simply put, when I had the good fortune to find participants who met the inclusion criteria, and who were willing to participate, I did not hesitate to recruit them even if it meant that the majority of patient participants were recruited from the same hospital unit. In retrospect, I was fortunate that recruitment and data collection unfolded as it did, as I was able to complete most of my data collection prior to the COVID-19 pandemic. Had recruitment occurred at a different pace, or had I waited to try to distribute the sample more evenly across the three units, I likely would have had to halt my data collection for several months, delaying completion of the study.

It could be argued that my role as an observer is another possible limitation. It could be that my presence as an observer might have affected the interactions that staff normally had with ALC patients, causing staff to act differently than they might normally. Thus, what I observed and recorded might not have been an accurate representation of daily and regular care. This is where spending as much time as I did on the one unit might have been beneficial. Over time, I found that I was able to build relationships with staff as they remembered who I was and why I was there, and became comfortable with my continued and frequent presence. I was always careful to present myself as an impartial observer, and I found that staff started to come up to me when I came on the unit to report to me how the patients I was spending time with were doing.

Initially, I considered accessing patient documentation as an additional data source when I was planning this study. I thought that there might be important information in nursing and physician notes in terms of what they could reveal about what was happening for patients during their hospitalizations. In the end, I decided to focus primarily on the patients themselves and what they could reveal about their hospital experiences. This was because I was not sure how

useful patient documentation would be in answering the specific research question that I had developed, and felt that this type of data might distract and detract from the main purpose of this study which was to gain access to the patients' experiences and perspectives. While forsaking this additional layer of potentially useful and informative data might have limited the direction in which this work went, ultimately I am satisfied with the outcome of the data collection strategies that were undertaken, particularly as the observation sessions resulted in very rich and dense data.

In addition, it might have been useful to interview physicians, social workers and other health care professionals, and not just nurses. Originally, I had planned to recruit a variety of different health care professionals who care for ALC patients living with dementia. However, as I began data collection and was reflecting on the nature of the work I was doing as a nurse researcher interested in developing useful nursing knowledge, I decided to limit my sample of health care professionals to nurses. I felt that this was in line with the specific disciplinary orientation that was guiding this study. This also made sense when considering that nurses tend to spend the most time with patients in the hospital setting. This is a strength in this study, in that this decision has relevance within the framework of an ID study. In terms of limitation, there might have been valuable perspectives from other health care professionals that might have contributed to useful knowledge and understanding. However, limiting the health care professional sample to only nurses did help to provide an important focus for this work.

## **9.7 Reflecting on ID**

In regards to the disciplinary orientation of ID work, I would like to take this opportunity to reflect on using this particular approach to research. As a practicing nurse with a research

question that had its roots in the practice setting, I was immediately attracted to the idea of using ID for my dissertation work because of its focus on the development of applied and disciplinary knowledge. My research question's epistemological orientation, in that my intention was to provide useful knowledge for practice and for improving the care of ALC patients living with dementia, was well suited to an ID study. Furthermore, ID's interpretive orientation and recognition of the socially constructed nature of human experience aligned well with not only how I see the world and view nursing, but also worked well within the context of this study. The flexibility inherent in ID work ensured that I was able to adapt to the different units I spent time on, as well as to each patient participant's daily reality as a long-term hospital patient. Certainly, being able to successfully navigate the complexity of the dementia and ALC experience required an appreciation of the relativist nature of subjective experiences. Dementia tends to be powerfully socially constructed and approaching this study from an ID grounding that acknowledged this was important throughout this study.

Overall, I am convinced that ID worked very well for this research study. ID's grounding in disciplinary knowledge (Hunt, 2009) helped me to stay focused, and make useful decisions as the study proceeded. For instance, there were many times throughout this process where I started to find myself exploring lines of thought that were potentially and theoretically interesting but did not necessarily align with the disciplinary focus of this work. The world of research is an unimaginably vast and far-reaching intellectual space. If not approached in a thoughtful and intentional way, I can imagine that one could easily get off track and speculate and postulate oneself into all kinds of unhelpful places.

As an experienced nurse, it made sense for me to choose an approach to inquiry that was framed by my discipline's orientation. This does not mean that this study could not have been

approached using other research methodologies. This is one of the wonders of research and inquiry, that there are many different ways to approach problems and concerns. However, given that the research question guiding this work first emerged in nursing practice, and the goal was to improve patient care and contribute to nursing knowledge, utilizing ID has provided me with a meaningful and useful approach from which to undertake nursing research. Some have criticized that ID is not a distinctive qualitative approach in and of itself, and is in fact part of the grounded theory movement (Berterö, 2015). However, I am persuaded that as a methodological option developed for use by researchers to add to disciplinary and applied knowledge (Teodoro et al., 2018), that this was an approach to research that was not only well suited to this dissertation study, but is also a qualitative research approach that has much to offer to applied disciplines.

## **9.8 Conclusion**

A curious but fundamental aspect of life is that once we get to the end of something, we often find ourselves back at the beginning. Thus, as I bring this dissertation to a close, I cannot help but reflect on how this research project first started. The initial idea for this work emerged in my nursing practice, when I first started to question what was happening for ALC patients living with dementia in hospitals. This eventually led to the work that has been detailed in this dissertation, a study focused on the perspectives and experiences of these patients, with the goal of situating the knowledge that has resulted firmly in the context of care, specifically nursing care.

Utilizing an ID approach to qualitative research, this study has brought to the fore what it is like for ALC patients living with dementia to spend long periods of time in the acute care setting. It has detailed the daily experiences of these individuals, their perspectives and

understandings, as well as the challenges and distress they often have to confront. This study, and more importantly, the patients who participated in it, have reminded us of the essential personhood and social citizenship of each person that nurses come into contact with in practice, regardless of diagnosis, age or cognitive status. In addition, this study has shown that while older patients living with dementia are provided with the kind of hospital care that ensures that they are fed and washed, they are not always nurtured, nor is their ongoing health and wellbeing consistently facilitated or fostered in person-centered ways. While attention to basics matter to them, the patients do not always feel listened to, nor is their agency always recognized. As ALC patients, especially as persons living with dementia, the pervasive liminality that characterizes their hospitalizations and the poor fit of existing services in terms of their specific needs are unfortunate and require addressing.

Overall, the findings that have come out of this work have several implications for nurses. Nurses need to acknowledge, protect and foster the abilities and strengths of older patients in the hospital, and this involves challenging practices and understandings that are firmly entrenched in our system of care, especially when it comes to the care of those living with dementia. We also need to challenge the behavior narrative, as well as the labeling that is prevalent in hospital care and further stigmatize patients. Finally, it behooves us as nurses to recognize the significant transition that is the ALC experience. This is so that we can ensure that we meet these patients in a caring and inclusive space, where their ongoing needs are recognized and addressed, particularly for ALC patients living with dementia, who are waiting for home.

## Epilogue

### Words to End With<sup>11</sup>

We talk about the weather for a bit  
I ask her what time of year is her favorite?  
She tells me that it is Spring  
“Because everything is new”

I ask her what her favourite food is?  
And she tells me that it is meringues  
I ask her if she sleeps well?  
She says that she’s often woken by her neighbor  
“He gets on my nerves,” she says

I say to her “Have you been watching the news?”  
She says, “You mean about Trump?”  
I nod and she laughs,  
“I think he’s a load of crap”

I ask her how long she has been here  
And she says to me,  
“I’m not sure,  
It feels like ages”

I ask her if there is anything  
That makes good care?  
She says, “just listening”  
When someone listens  
“It really means something,”  
She tells me....

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<sup>11</sup> Written with excerpts from Field Notes for Mrs. Rogers 11.15.2019-11.21.2019

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## Appendix A: Study Information Letter (Patients)



### Dementia and the Alternate Level of Care Experience

#### Study Information Letter: Patient Participants

#### Are you interested in participating in a research study?

I am conducting a study to explore the care experiences of Alternate Level of Care (ALC) patients living with dementia who are currently hospitalized.

This research involves observing the daily activities and care of ALC patients with dementia, including observing time spent with family and hospital staff. I will also be talking to family and hospital staff about what is happening on hospital units when it comes to the care of ALC patients with dementia. More importantly, I would like to be able to talk to ALC patients living with dementia, as well as spend time observing their care experiences.

I believe that this research is important, as it will provide valuable insights into how we can provide the best possible supports and care for ALC patients living with dementia. Findings from this study will be shared with patients and their families, health care professionals, policymakers, administrators, health care decision-makers and educators to inform and improve care.

This research is part of my PhD studies at the University of British Columbia. [Hospital/Health Authority name] is supportive of my research and has kindly agreed to act as a study site. The primary investigator is Dr. Alison Phinney, a registered nurse and nursing professor at the University of British Columbia. She can be reached at [REDACTED].

If you are an ALC patients living with dementia and are interested in learning more about the research, please contact me and I can provide more information about the study. Please note that this does not oblige you to participate. After I provide you with additional study information, you can decide whether you would like to take part.

If you have any questions, please feel free to contact me at [REDACTED] or [REDACTED]

I look forward to speaking with you about my research.

Kind regards,

Mariko Sakamoto, PhD candidate

\*\*Participation in this study is entirely voluntary. You may refuse to participate and can withdraw from the study at any time. Your decision will in no way affect your hospital care

## Appendix B: Study Information Letter (Family Members)



### Dementia and the Alternate Level of Care Experience

#### Study Information Letter: Family Members

#### Are you interested in participating in a research study?

I am conducting a study to explore the care experiences of Alternate Level of Care (ALC) patients living with dementia who are currently hospitalized.

This research involves observing the daily activities and care of ALC patients with dementia, including observing interactions with family and hospital staff. I will also be talking to family and hospital staff about what is happening on hospital units when it comes to the care of ALC patients with dementia. The perspectives of family members will be important and helpful in providing information that I might not be able to have access to as an observer, or from interviews with hospital staff.

I believe that this research is important, as it will provide valuable insights into how we can provide the best possible supports and care for this population of hospital patients. Findings from this study will be shared with patients and family members, health care professionals, policy-makers, administrators, health care decision-makers and educators to inform dementia and ALC care policy and practice.

This research is part of my PhD studies at the University of British Columbia. [Hospital/Health Authority name] is supportive of my research and has kindly agreed to act as a study site.

If you have experience as a family member caring for ALC patients with dementia and are interested in participating in an interview, please contact me and I can provide more information about the study. Please note that this does not oblige you to participate. After I provide you with additional study information, you can decide whether you would like to proceed in taking part. The principle investigator of the study is Dr. Alison Phinney, a registered nurse and professor of nursing at the University of British Columbia. You can contact her at [REDACTED]

If you have any questions, please feel free to contact me at [REDACTED] or [REDACTED]

I look forward to speaking with you about my research.

Kind regards,  
Mariko Sakamoto, PhD candidate

\*\*Participation in this study is entirely voluntary. You may refuse to participate and can withdraw from the study at any time. Your decision will in no way affect your family member's care.

## Appendix C: Study Information Letter (Nurses)



### Dementia and the Alternate Level of Care Experience

#### Study Information Letter: Health Care Professionals

#### Are you interested in participating in a research study?

I am conducting a study to explore the care experiences of Alternate Level of Care (ALC) patients living with dementia who are currently hospitalized.

This research involves observing the daily activities and care of ALC patients with dementia, including observing interactions with family and hospital staff. I will also be talking to family and hospital staff about what is happening on hospital units when it comes to the care of ALC patients with dementia. The perspectives of hospital staff will be important and helpful in providing information that I might not be able to have access to as an observer, or from interviews with patients and family members. Participating in this study will involve taking part in a 30-90 minute interview about the care that ALC patients with dementia receive in hospital. The interview will be audiotaped.

I believe that this research is important, as it will provide valuable insights into how we can provide the best possible supports and care for this population of hospital patients. Findings from this study will be shared with patients and their families, health care professionals, policy-makers, administrators, health care decision-makers and educators to inform dementia and ALC care policy and practice. This research is part of my PhD studies at the University of British Columbia. [Hospital/Health Authority name] is supportive of my research and has kindly agreed to act as a study site.

If you have experience caring for ALC patients with dementia and are interested in learning more about the research, please contact me and I can provide more information about the study. Please note that this does not oblige you to participate. After I provide you with additional study information, you can decide whether you would like to proceed in taking part.

If you have any questions, please feel free to contact me at [REDACTED] or [marikoliette.sakamoto@alumni.ubc.ca](mailto:marikoliette.sakamoto@alumni.ubc.ca). The principle investigator of the study is Dr. Alison Phinney, a registered nurse and professor of nursing at the University of British Columbia. You can contact her at [REDACTED]

I look forward to speaking to you about my research,

Kind regards, Mariko Sakamoto, PhD candidate

**\*\*Participation in this study is entirely voluntary. You may refuse to participate and can withdraw from the study at any time. Your decision will in no way affect your employment status**

## Appendix D: Sample of Selected Field Notes

October 24, 2019 0953 hours

The ward is preparing for 1000 hrs rounds... I am sitting by Mrs. Wong.

She appears to be sleeping deeply on her left side. She appears to live with contractures. There is a skin alerts sign over her bed dated from March of this year. All the other beds (4 bed room) are occupied. Everyone seems to be sleeping.

There is a TV on, some type of sports activities on, the patient in the bed (neighbour) drifting off and on in sleep, occasionally snoring (watching curling).

It's quiet in the halls this morning. I can hear a few drawers being opened and closed.

Mrs. Wong's curtains are partially closed, the blinds are closed by her side of the room but it is bright in the room.

What must it be like to exist in frequent slumber? Is Mrs. Wong in a liminal state?

She looks like a child, curled up on her side. Tiny feet, ankles exposed. Pink but slightly dry and cracked skin.

The PA system briefly interrupts the quiet tremors of the room, curling, color commentary and snores to announce » morning team it's time for rounds ».

1002 hours: A loud beeping noise (undecipherable writing) I'm not sure what it is...? It doesn't last long, maybe five seconds.

Mrs. Wong raises her head for a second... then another announcement for rounds.

The TV is now spewing commercials, fast food and other ads... it's in some ways just like sitting in the house (anyone's house) with everyday background noise at times. Snores as if my husband is napping on the couch. But it's not home-like really, especially as there is a fourth announcement for announcing icare Rounds, static on the PA system as there is someone saying "Hello, Hello?"

Mrs. Wong's neighbor across the way has kicked off his blankets, should I cover him up? I am not his nurse, but if I was here as a visitor I would probably pop over to make sure he's covered... Although I think he's hot, probably wants to free his legs.

What do I see: there is a built-in storage unit on the far wall. The top shelf has stacks of adult diapers, color-coded for size. There are save a day trays and blankets stacked below.

1008 hours: there are towels in blue pads and sliding basket drawers, with soiled linen hampers.

1010 hours: Mrs. Wong is sleeping deeply. At 10:16 she opens her eyes and mumbles to herself, patting her pillows (trying to re-arrange them?) I'm not sure if she can see me, her eyes are open and she periodically fidgets and scratches

What do I hear: the curling game continues in the opposite bed. When you listen carefully there is a slight sound of a fan... Air circulation.

Mrs. Wong seems very itchy, she probably needs some moisturizer.

1016 hours: observations when husband arrives.

When the husband arrives he puts down the bottom side rail and set down and leaned over to pat her hand/back. Mrs. Wong responds and they quickly clasp hands.

The husband states that Mrs. Wong usually only respond to him. She is often not understandable when she speaks and her is the only one who can understand her, although not always.

He is not sure what language she is speaking. He says that she often asks for something to eat, that she likes to eat sweet things. His routine is to come in early, usually at 7 AM to help with the morning routine, wake up/wash/breakfast as she can get agitated.

The husband says “she has no control” that “she is like a child”. When she gets agitated she can call out according to the husband. She will let get red in the face. According to the husband “it is not good”.

He also will come back around 1030 after he leaves to eat his own breakfast around 9 o'clock after he has fed her and she usually settles down for a nap at that point.

He will stay until every afternoon when he leaves to help out with his grandson. Then returns around dinner time and will stay until she goes to sleep. He says that she used to have lots of trouble at night but it seems she does well at night now with a sleeping pill. She takes all of her medications crushed, usually in applesauce.

He seems happy to chat. I wonder how he spends his time in all the long hours that he is here? He says that sometimes he and she will talk. Sometimes she remembers events from the distant past and he and Mrs. Wong talk a bit.

Mrs. Wong sleeps throughout most of the remaining time that I am present. Sometimes she will open her eyes, rearrange yourself on the bed and then fall asleep again.

The husband seems concerned that she might be sleeping too much during the day.

She doesn't walk anymore because she has “no control”. The husband indicates that she can stand...? She has some residual left-sided weakness from the CVA.(according to the husband)

The husband says that she had a stroke in February, was that first hospitalized at [hospital name] where she had surgery to her head (cranial bleed). Then was moved to [hospital name] a month later.

The husband says that she's been here at [hospital name] for seven months. He says his health has not been great since then, he has high blood pressure, he has some high sugars. He's not taking any meds, has run out and has no time to see his GP, who only works Saturdays.

He and Mrs. Wong are waiting for an LTC bed in [city name] [name of care home] which will be close to home for him, as he has some difficulties driving at night.

It is apparent that he feels the need to be present for his wife frequently during the day, otherwise she will become agitated and he's the only one who can soothe her.

During the time that I am there, the nurses seem to be changing a neighboring patient. Behind the bed curtains we can hear him calling out “Help! Help!” Frequently.. The nurses reassures him, tell him he will be okay.

The husband indicates that if he wasn't present during care, that Mrs. Wong will call out like that.

What I hear: it becomes noisier on the unit as it approaches midday. Visitors arrive, patients for helped out of bed. Most in the room seem to need at least two person transfers. Mrs. Wong seems unperturbed by the increased noise, napping on and off, but her husband states that often the noise will disturb her.

He feels that she is safe here in hospital, especially at night because she's getting 24 hour care.

He also says that she gets bothered easily by the pajamas and down that she wears, she has in the past disrobed. She doesn't like the incontinence pads, they irritate her.

During my observations, she is seeing to pluck at her clothing, to reach into her pajamas and scratch at her skin. She also plucks often at her blankets, and fidgets with the towel that she periodically holds...biting at loose threads.

Often the husband will reach out to grasp her hand or slide his hand up one of her arms, he will say her name, he says she likes that and will recognize her name. She doesn't remember his name but will call him husband.

1200: I leave when the lunch meal comes. I've been there for two hours. The husband says he will feed her, it looks like today she will eat in bed. Sometimes she is up for lunch, other times up in her wheelchair later in the day.

The husband says he is agreeable if I come for a morning session of observation to be present during the early morning routine. I will come next week October 29 at 0700 hrs.

### **October 30, 2019 1515 hours**

Mr. Powell is asleep when I come in. I sit by his bed, not wanting to rouse him. I've been told by the team that he will be leaving tomorrow for a care home.

The room is quiet, two student nurses enter the room and toilet the neighboring patient.

Mr. Powell wakes up and sees me. I ask him if he would like to sleep some more but he says no, immediately telling me that he's had a good news. He seems quite pleased.

#### ***Remainder of field notes based on jottings***

I asked which is looking forward to in terms of moving to the care facility.

He is looking forward to getting to know other residents in been able to chat with people. Despite there being three other people in his hospital room, it is hard to get to know other people.

He like seeing the staff, the nurses or the "the girls" as he calls them. He explained that he will say hello to them, and waves to them but he feels bad that he couldn't always remember their names. I asked him how it has been for him in the hospital and he said that the care has been "excellent"... but then went on to rave about the food. Breakfast and lunch are great, especially the soups he explained... dinner is just okay.

He is looking forward to seeing if there's any people he already knows at the care home. I asked him how he felt it's been in hospital, if it had been hard to wait several months? He said no but it didn't bother him to wait, that he is easy-going.

While we were talking, the ward occupational therapist pops by to talk about his discharge tomorrow, asking whether his wife would be able to arrange for a wheelchair, as the chair he has been using belongs to the hospital.

He stated that they do have a wheelchair at home and that his wife will be able to bring it to the facility. The occupational therapist then left.

During the last 30 minutes of our visit, the room became busier and noisier. Mr. Powell's neighbor directly across from him started yelling out. I wasn't sure what this person was saying but it sounded like hello. Throughout our entire visit, the patient in the pajamas wandered in and out, usually standing a few minutes by the window then wandering out again. The last few times he came in, he would quickly leave covering his ears with his hands due to the yelling. I counted that he came in and out six times.

Mr. Powell didn't seem perturbed by the yelling, shrugging his shoulders when I asked him if it bothered him. He told me that overall he has "done well in life" perhaps reflecting on the new transition he is heading towards tomorrow, moving to a care home, moving to new home.

He told me he was luckier than most as he has a good memory, in part because of training he received as a mason. He also told me that he's "been around long enough to spread the message everywhere..." he then proceeded to recite a mason poem/pledge to me. He remembered most

of it, faltering at times. It starts like this:" there is a land where all are equal, we are hastening to it fast"

I'm not sure about the ideas in this poem and what he meant by "spreading the message". We weren't able to explore this idea, as he tried to recite another poem and seem to be reciting the same one again, but this time with a fair amount of difficulty.

I told him that the poem is lovely and seems to have the beautiful message. He seemed pleased, smiling. I told him I would take my leave and I clasped his hand, his grip strong in mine. I wished him well with his move tomorrow and said goodbye.

### **November, 12 2019 1520 hours**

When I first got on the ward this afternoon, I immediately saw that Mrs. Ho's bed was empty. The first thing I thought was that perhaps she had passed away! I went to the nursing station and asked the nurse where she was. The nurse told me that she had moved to another room on the floor and told me the room number.

Relieved, I walked around the unit until I found her new room.

She is now in a four bed room, her bed is in one of the corner sections closest to the entrance. All the other beds are occupied. I found her sitting up in her broda chair. It appears she is sitting on a sling, and the chair's tray was attached in front of her.

I smiled and said hello, and she sat up a bit from her chair which was slightly inclined. She seemed happy to see me, smiling broadly and reaching out to grasp my hands. I ask if I can sit with her and point to the bed next to her. She nods and I take this as assent. She starts to chat with me, in her own language. And she made a sound of exclamation, it sounded like an exclamation of pleasure to me. Just then, her neighbor in the bed beside her, unseen because the curtain was drawn between their beds, said very loudly" please be quiet!"

Mrs. Ho and I share a look, as if to say, who does that guy think he is!

1540 hours: Her neighbor across the way from her appears quite sick, he has two family members by his side. He is on oxygen, some type of high pressure device. I hear a family member say that he has aspiration pneumonia. Two nurses are at his side conducting an assessment, the curtain at the foot of his bed is slightly open and Mrs. Ho is watching carefully. A visitor enters during this activity.

At this point, I notice a magazine by her bedside, it appears to be in her language. I bring it over and offer it to her and she accepts it. We look through it together, sometimes she says something in her language and points at certain pictures.

The nurses have completed their assessment of the neighbour across the way. They both come by to say hello to Mrs. Ho. One of them says "Oh, she's here now, this is better" apparently referring to the room change. "Hi Sweetheart" the nurse says to Mrs. Ho speaking to her directly. Mrs. Ho smiles and nods hello. The nurse then leaves only to return in a moment with two hand towels clasped in her hand. She is holding them balled up and shows them to her.

Mrs. Ho yelps when she sees the towels, she seems happy and surprised. The nurse makes a throwing motion with her hands and says "catch. She then throws them at Mrs. Ho who catches them in her hands. And then attempts to throw them back at the nurse when the nurse motions for her to do so. She seems to enjoy the throwing game, does not seem distressed or insulted by it. It lasts only for a moment and then the nurse has to leave.

1550 hours: We spend some time together looking through the magazine. At times she will point to a picture in it and make a comment, which I can't understand.

1602 hours: A man with a beard and a chart enters and says hello to us. He is a geriatrician and asks if I can speak her language. I explain who I am, and he says that he has come to see how she is doing because she has been agitated lately, particularly at night. She smiles at me, and he remarks "she likes you!". He leaves saying he will speak with her nurse. She looks at me and makes a face (a moue with her mouth) and then runs her hand over her chin, as if she has a beard. She shakes her head, I don't think she likes his beard!

I notice that her legs are hanging off to the side a bit on the chair's footrest. I ask her if I can help her, motioning to her legs and she nods. I notice that her legs, which are bare where her pj bottoms are hiked up, are quite cold to touch. I offer her the blanket which is folded by the end of her bed, but she shakes her head no.

We continue to sit together, she alternately leafs through her magazine, or watches the comings and goings in the room. At times she will point and I will follow her direction. I'm not sure what she is pointing at but I look in the direction she shows me. She appears to be watching what is happening at the other beds in the room. At times she will reach over and get my attention with her left arm, ever attentive and expressive.

I've noticed since I came in that her teeth are not in. I wonder why as it is quite noticeable when she smiles that she has no teeth left in her mouth.

1607 hours: Two other nurses provide care to the neighbour kitty corner to her bed. Throughout this time with her I have been taking jottings in my notebook. I usually leave the notebook in my bag at my feet and when I want to take notes, I try to show her my pen and book and say to her "Is it OK if I write?" She nods each time I ask this.

The neighbour next to her is still leaving messages on his cellphone. We still can't see him. She has begun to stack up the magazine, there are several loose pages in it that have been torn out or come loose over time. At times she will fold the hand towels that are still on her tray or will wipe the magazine down with a towel. At one point, she uses a dry towel to wipe at her face. I wonder if she would like a moist towel?

1610 hours: The two nurse who have just completed care across the way start to leave the room, and stop by to say hello. "You are one of my favourites!" She smiles widely up at him.

One of the nurses explains that she was moved to this room because she needs the overhead lift, which is installed in this room. This would explain the sling she is sitting on, and I think to myself that her mobility must be decreasing....

I've noticed that today she smiles and nods when people come and talk to her, but then gives me a "knowing look" when they leave...as if she doesn't think they are that great..

One of the nurses returns to the room to provide care to the very sick patient across the way from her. From where she is sitting it is apparent that she can see what is happening by the bedside as the curtain is open a bit. She reacts with surprise at whatever she is seeing. This is apparent by the way she sits up a bit suddenly, and her mouth opens in surprise.

1620 hours: The physiotherapist has come by to the neighbour beside her. We hear them speaking about a trip to Pheonix that the physiotherapist recently took. It sounds as if the neighbour is getting up. Suddenly he walks by us, with the phsyiotherapist holding his gown closed. He is using a walker. He says hello to us as we walk by. She gestures to me as he walks by, she does not seem too impressed by this person, as if she remembers that he told her to be quiet...maybe she does!

Suddenly she makes a face, as if she is imitating someone she doesn't like, and we both burst into laughter at the same time. It is a nice shared moment.

1627: I decide to see if she would like to wash her face and point to one of the towels on the tray and say “can I moisten it?” She nods...I’m not sure if she knows what I mean but I go and run some warm water over one of the towels and wring the excess water out. Bringing it back to her, she accepts it and immediately and thoroughly washes her face and neck.

1635: One of the nurses comes in and leaves a luer lock syringe and some plastic bags on the bed. She looks at the equipment with some alarm. He comes back in and tells me that he is going to take a urine sample from her Foley bag and starts to reach up her leg for the port...she looks concerned and starts to move her legs. “Don’t kick,” he says... I touch her arm and start to speak in a reassuring voice, explaining that he is going to take a sample and that it won’t hurt her. She looks at me, and the nurse is able to finish drawing the sample, then leaves.

Right after this, another nurse comes in to empty her foley bag and measures it.

1640: Shortly after, another nurse (this is the fourth one to come by) comes in with another syringe and says that she has to give her an injection. She looks at Mrs. Ho, and notices that she has a down jacket on over her pyjamas. She then looks at her legs, I think she is going to inject her leg. She starts to reach for her, then decides to stop and say “hi” waving to her. I start to talk again with Mrs. Ho explaining what the nurse is doing. The nurse quickly injects her leg and leaves, Mrs. Ho doesn’t appear to have noticed the care/med administration.

At 1645: the same nurse returns with crushed medication in a small plastic med cup, it looks like it has been mixed with apple sauce. She says, the med will “calm her down”..perhaps this is a new medication that the doctor has ordered? Mrs. Ho accepts the spoon with the mixture. The nurse says “swallow it” and returns with the small cup full of tap water, giving it to her. She swallows but starts to cough a bit, as if the mixture and the water have not gone down well. The nurse watches carefully until she stops coughing and then leaves. I feel like they could have given her a cup with a straw and a bit more water, as she clears her throat and coughs a bit more. (I also think this as her urine is quite dark in colour in the foley catheter)....

At 1650 I gather my things and say goodbye...she looks at me and says something, it sounds like a question. She seems uneasy, I feel that we are not connecting as we had earlier. She seems confused by what I am saying and does not say goodbye or nod, when I say thank you and good bye.

### **November 15, 2019 1900 hours**

Joint observations for Mrs. Wong and Mr. Lee

Mrs. Wong is up in bed with her husband at her side. The husband looks tired. She is chatting with him.

7:15 PM the nurse came by to check in. Asked the husband about when to settle her for the night. He said at about 8 PM.

I often noticed the staff are very respectful of the husband as if he is one of them, but more... the ultimate caregiver.

Mr. Lee is half inclined in bed, he smiles and shakes my hand when I say hello. He grasps my hands and I sit next to him. He clasps his hand for a bit, then runs his hands along the side rails, or alternatively pats his bedding. He seems wide-awake

7:26 PM: conversely, Mrs. Wong is at times sleepy looking but then will hunch forward, talk quietly and pull at the bed clothing.

Mr. Lee frequently looks over at Mrs. Wong’s husband and will wave at him. I ask him at one point how his day was any gives me a thumbs up.

7:30 PM: the nurse comes into do vitals. The neighbor by the bathroom does not seem to be doing well. He is off the ALC list and has been put on a sliding scale. He has a fairly full dinner plate in front of him. I don't think he has been eating well.

7:35 PM: she (LPN) comes to Mr. Lee and shows him the blood pressure cuff. He puts up his arm for her. She says "you know the drill". She puts the pulse oximeter on his finger which he promptly removes but allows her to put the thermometer in his mouth. She thanks him" thank you!" (She wears gloves)

And Mrs. Wong accordingly repeats "Thank you!" (it seems she is heard the nurse from across the way) Her husband helps the nurse get the vitals. They hold her left arm in place while the blood pressure is taken, as well as axilla temperature. She is relatively calm and the vital taking is over quickly.

Mr. Lee continues to pluck at his blankets. It's very quiet here this evening.

7:40 PM: Mrs. Wong and her husband chat quietly together. He tells me that "her skin is not good" and he also says that he will rub it in the evenings, maybe to help with circulation? Mrs. Wong chats to herself. Her husband says she "says nothing" when I ask what she is saying.

7:47 PM: Mrs. Wong sits up and pulls the legs of her pajamas up her leg, past her knee. Her legs are tiny. Her husband sits by the side of the bed, head bowed, holding onto her leg and she sits up in bed, chatting to herself. A nurse comes by and drops off the evening snack, the husband says thank you in Cantonese (shi shi) and Mrs. Wong says it too.

7:52 PM: I can hear the neighbor by Mr. Lee snoring. Mr. Lee sometimes will vocalize. The other neighbor by him is reading the paper, and we can hear the swishing of pages being turned. We hear the crusher on the medication cart crushing pills and the nurse comes into give the neighbor his evening medications. He says "no, no!" But very quietly compared to previously. We hear his bed being adjusted after his pills are given.

The nurse checks when Mrs. Wong last had a bowel movement. She went yesterday but the husband tells the nurse that it was very hard. Perhaps she will get a stool softener tonight? Another nurse comes in to ask if it is time to change her pad. The husband raises is the bed to waist height in preparation to help the nurses.

8 PM They start to turn her to change her but as usual her voice rises. "Hiya, hiya!", she says. The nurse chats in her language and her husband reassures her the whole time. The other nurse drops off crushed medications and applesauce. The husband will give the medication to her afterwards. The nurse chats further in their language. She says thank you many times in her language and Mrs. Wong says thank you back, several times as well. However, when the husband draws the curtains, she is upright in bed somewhat agitated and he comforts her. The bed is readjusted and lowered and he makes her comfortable.

8:05 PM: they start care for Mr. Lee. Two nurses come in and lift the bed. "Hey" Mr. Lee calls. "All wet", the nurse says. "hey oh!" he cries. They talk it through as one nurse knows him better and instructs that it helps to have him hold the rail. I hear the nurse say that the family is concerned about his skin, but they don't see a sore on his backside. "Hey oh!" he cries again but overall it seems that care is going smoothly. The reposition him. They are now trying to take his dentures out and he yells loudly. "Good, thank you" they say as the dentures come out.

8:11 PM: care is done, the bed is lowered and the head down. He's all tucked in.

The husband has been giving Mrs. Wong her nighttime medications, crushed and mixed with applesauce and pudding. I've now moved to my usual spot at the window as I think Mr. Lee is going to settle for the night.

8:13 PM they're now providing care to Mr. Lee's neighbour. "No, no, ow" he says.

H lies on his back, his mouth open and round without his dentures.

8:16 PM: Mrs. Wong is still taking her medications. The husband has prepared the medications and mixers on the spread out paper towel on the bedside table. He is meticulous and careful in his care, and preparation.

8: 16 PM Mr. Lee is still awake. I wave to him and he waves back, then he leans onto his back, hands clasped on his chest.

8:28 PM: I do a quick walk through the unit. During the evening there are quite a bit fewer people around. The nursing desk looks empty. Nurses are in the rooms helping to prepare patients for the night, or at medication carts doling out nighttime medications. There are a few wheelchairs parked in the hallway. In the common room where they hold music therapy sessions, the space is now full of wheel chairs and Broda chairs, all parked for the night. The husband is trying to tuck Mrs. Wong in for the night. He lowers the bed and covers her up. I asked if he wants the lights off, he says "okay, okay," but seems preoccupied. I suspect he wants to settle her...

Her eyes are closed, they seem to be in a restful repose together. I won't say anything more to him.

I can hear the neighbor by Mrs. Wong's bed leafing through his newspaper, the other neighbor periodically snoring loudly. The nurse is looking through the medication record in the hallway going through the drawers.

Mr. Lee lies quietly on his back, still awake. It is quite bright in the room with the overhead lights on.

8:33 PM: the nurse comes in with crushed medications for Mr. Lee. She has gloves on. She brings water. "Papa" she calls him, "I've got your pills"

She raises the head of the bed, he calls out. She gives his medications mixed in prunes, he opens his mouth wide to take it, then take sips of water she offers from a cup straw. He coughs once, she wipes his mouth. She lowers the bed and fixes his blankets, which have become all twisted up. "Eyy Oh!" he yells twice. She leaves and he is tucked up to his chin.

8:38 PM: she turned the lights out overhead. Mr. Lee yawns. Mrs. Wong's eyes are closed and her husband remains leaning over, his hands on her chest, her hands over his.

8:40 PM: I hear a call bell ringing in the hallway, the nurse comes in. It is the neighbor's call bell. The nurse offers him a warm blanket.

8:45 PM: all of the lights are now out in the room. The nurse kindly checks on me "Are you okay there?"

Mr. Lee and Mrs. Wong are both still awake. However, Mr. Lee is now quite still, lying on his back. His arms rest quietly under the blankets. Mrs. Wong is chatting again, her husband seems impatient, tries to get her to settle.

There is some noise from the hallway as the nurse goes through the medication cart and the call bell is pinging again. All of these noises might be stimulating Mrs. Wong?

Meanwhile, Mr. Lee looks to be drifting off. I can hear Mrs. Wong rubbing at her mattress. She is definitely still awake despite her husband's best efforts.

I will take my leave for although I don't think I am affecting her, I'm not sure. I am sitting here in the dark but perhaps this is distracting to her husband and Mrs. Wong is picking up on it.

8:50 PM: I take myself from the room. Mrs. Wong is sitting up in bed, itching her legs and seems quite agitated. I sit outside and observe the ward (from my vantage point in the hallway). I hear a monitor beeping, and care being provided in another room.

8:55 PM: The husband comes out to tell me that she's been dreaming and now she needs to "cool down". Once she has cooled down, he will help her to go back to sleep. He goes back into the room and I hear Mr. Lee coughing and calling out briefly he must still be awake too. I decide to take myself from the unit. All is otherwise fairly calm with nurses quietly talking to one another about patient care and others organizing their medication carts. It is 9 PM and I take my leave.

### November 20, 2019 1700 hours

As I come onto the ward this afternoon, I see one of the family visitors of Mrs. Wong's neighbors. She tells me that Mrs. Wong left today, but she doesn't know where she is gone. Perhaps the bed she has been waiting for at the facility of her/ her husband's choice has come available. As I walk by her room, I see that her bed is now unoccupied and made up waiting for a new patient - it is odd not to see her and her husband there.

Mrs. Rogers is up in bed, sitting with the head of the bed raised. Her dinner tray is beside her. I say hello and she says, "it's nice to see you."

I ask if I can sit with her and she says, "yes."

The nurse comes into give her crushed medications in applesauce, and a potassium suspension to drink.

The care aide mistakes me for a family member and asks if I can help feed her dinner. I explain that I am not a family member and I am here to observe.

The care aide asks Mrs. Rogers if she would like to feed herself and she says "no."

The aid cuts up her food and sits by her side, perched on the bed, feeding her.

It really is busy in the room. There is now a new patient in the corner, with a visitor, receiving care. The rest of the patients are eating their dinner.

1708 p.m.: The care aid asks Mrs. Rogers how her food is, Mrs. Rogers says it is good, the aide then offers her her tea.

Mrs. Rogers has her glasses on, is sitting upright in bed and has a bib on. She looks to the side as she eats her dinner. We make eye contact, and I smile at her and she smiles back.

I am sitting at the foot of the bed.

The care aid makes minimal conversation but at one point does ask her if her husband was by to visit with her today.

Mrs. Rogers says yes, from what I understand he comes by every day, he uses a wheelchair and comes via handy dart.

1715 p.m.: The care aide asks me about my work. She tells me her daughter has a PhD in genetics and that it took her 7 years. It is nice that she's asking me about my work, but I do not elaborate other than to say that I am a nurse.

Earlier, when I moved Mrs. Roger's sling off the chair, I could smell the strong smell of urine on it.

1720 hrs. I hear chatting from the neighbor next-door, the other neighbor is sipping his tea, and the new neighbor is groaning as she's dealing with some pain.

I can hear someone talking with a raised voice in the hallway.

Mrs. Rogers appears to be eating well. The aid will give her sips of tea between bites. She is not rushing her.

Across the way, the other ALC patient waves that me. He points to his tray of food as if offering me some of his dinner. I smile and say, "no thanks", he points to his juice, picks it up and motions towards me. Again I politely decline.

1725 hrs.: dinner continues, it looks as if Mrs. Rogers has eaten all of her main meal and is now being offered dessert. It appears to be a rice pudding. She is a total feed tonight.

"How is it, good?" The care aid asks, and she nods with her mouth full.

### **Begin fieldnotes from jottings - after the care aide finished feeding her**

I ask her what her favorite food is, and she tells me that it is meringues.

I ask her what it's like being in the hospital? And she says, "it's different"

I ask her if there is much to do? She says that she keeps busy, but wasn't able to elaborate when asked how she does keep busy.

I ask her if she sleeps well? She says that she's often woken early by her neighbor, "he yaks" and "gets on my nerves" she says but that "he's alright really"

1745 PM she sips her tea that has been put in a plastic cup with a straw for a bit then suddenly speaks..." a few people I've met here, like you, are nice to talk to"

She struggles a bit to speak some more, it's obvious she's having some trouble with word finding.

"I find it so hard to talk!" She suddenly is able to say. Then she says, "there's not people here too... don't... A lot of people are frustrating in that way...(sips tea) they don't have conversations, they don't like to talk to you about usual things..."

She suddenly is able to say: "I would like to talk about politics for one thing, what people are thinking, things like that"

I say to her that it must be easy for people to forget that a patient in hospital is a person with his or her own interests, that the person can be effaced by the hospital gown... and other things that come with hospitalization. She says "definitely!"

I'll tell her that I like to talk about politics. So I say to her, "Have you been watching the news?"

She says, "You mean about Trump? » I nodded and she laughs." I think he's a load of crap" she says suddenly.

1750 p.m. Just then the nurse comes to take vitals. She apologizes for interrupting us, I told the nurse we've been talking about politics, so her blood pressure might be up I joke. We all share a laugh.

Mrs. Rogers watches as the machine measures her vitals. The nurse tells her that her blood pressure is better, "Your BP pill worked!" Mrs. Rogers smiles.

Once the nurse leaves, I go back and sit by her and show her some news reports about Trump.

We smile and laugh. I ask her what she thinks? "It's astonishing!" She states that he was ever voted in..."I think we're more sensible here"

At times, like this moment, her speech is very clear. She looks at me intently. "you have such an interesting face" she says then suddenly she starts to talk about gossip... And I can't quite follow what she's saying.

I listen, and her speech seems to drift off again. She seems tired and I decide to take my leave. I ask before I leave if I should take her bib off, which has been left on after dinner. "yes, take that off," she tells me.

I ask her if I can come and see her in the morning, and she says yes. I take my leave.

## December 20, 2019 1300 hours

Mrs. Ho was up in her chair when I came to her room. Her chair was reclined and she didn't have a pillow behind her head, she was sitting on her sling and her chair's tray was on.

When I say hello, she acknowledges my presence with a nod, but I am not as sure as I have been in the past that she recognizes me today... I motion with my stool that I would like to sit with her and she does not seem to object. She first smiled at me when I came up to her but then seemed confused as to who I was... Perhaps she doesn't remember me... Or she's not having a good day? (I wonder what a good day is for her)

I notice that there was blood tinged urine in her catheter bag and Foley tubing. (I wonder if she has recently had her catheter changed again)

She had a large towel draped over her tray, and she appears to be drifting on and off to sleep.

I notice that she has a new mattress, perhaps it is a pressure relieving mattress? It appears to be connected to a pump at the foot of the bed. I also noticed that she no longer has an ID bracelet on one of her wrists, rather she has a bracelet now on her right ankle. (I remember how she once was gnawing at the bracelet with her teeth- I think perhaps she has been trying to take her bracelet off).

When I say hello to her, she acknowledges my presence but I am not sure if she recognizes me as she has in the past? I notice that she has a slight grimace on her face at times, and I feel that she is not as happy today.

1310 hrs: the unit social worker comes in to talk to one of the neighbors. In the opposite corner to her bed, there appears to be a very confused patient, talking constantly to herself.

1315 hrs: Mrs. Ho is leaning over the left side of her chair, fingering and picking at the device/pump attached to her mattress (she is sitting quite close to it). It is well affixed to the bed frame and she is not able to move it. I offer her a cup of water as she appears to be annoyed with the pump, and she takes it from me and takes several sips.

It is quiet on the unit this afternoon, I can hear a few bells ringing intermittently.

1320 hr: I notice that she keeps hunching down in the chair with her hands reaching between the tray and her torso, she tugs a bit on her tray.

She's not interested today in talking with me as she usually is.

I am sitting right next to her and at time she does not seem to notice. We fold a towel together at one point, and she laughs for a bit at our joint activity.. (this is the large towels that was draped on a tray)

1323: she sits in her chair, she's facing the doorway and she can see all of the way down the hall. I look to see what she can see, I see an aide pushing a linen cart at the very end of the hall and a nurse sitting at a table in the hallway charting.

There is a steady sound of forced air from her mattress, as well as a slight high-pitched sound. This noise is accompanied by the gurgling breaths of her neighbor across the way. He looks to be on oxygen and his chest sounds quite congested.

1326 hrs. She has her hands grasping tightly over the front edges of her tray at times.

Alternatively she rubs a palm over parts of the tray, an intent expression on her face.

1327 hrs: A nurse or care aide comes in to check on one of the neighbors, and she waves to Mrs. Ho as she passes. Mrs. Ho smiles partially but otherwise does not acknowledge her. After this person leaves, she turns to me and talks to me in for a few minutes. She seems quite animated. Suddenly she starts to laugh, and then just as suddenly her face seems to collapse inwards, and for a few seconds it seems as if she is crying... And then her face clears.

Just outside the doorway is a med cart. At one point there are five staff members around the cart chatting, and Mrs. Ho watches intently then talks some more to me gesturing with her hands. (I wonder if she is talking to me about the staff members?). I can hear the staff members around the med cart talking about a patient who is aggressive...

1334: She puts her right elbow in the space between her tray and her body below it, she uses her elbow as leverage to ease some of the pressure from the tray... Her eyes are open wide in concentration and her chin is jutting forward as she does this. She has managed to get her right hand under the tray now and is banging her fist under it, and uses her left hand to slap the surface twice. While she's doing this, it seems to me that she has entered her own space... she does not look at me or talk to me during these times. She seems quite intent on what she is doing. I see the tray shift a tiny amount, but it is securely tied with a strap that connects behind the chair.

She then stops banging her tray.

1338: At this point she is alternating between sitting back in her chair, to leaning forward and pulling herself forward with her hands grasping the front edge of her tray as leverage.

It seems it is hard for her to sit still...(and I wonder if she is very uncomfortable?)

1340: A care aide or a nurse sees her from the med cart, and comes to say hello. "Hi mama" she says. Mrs. Ho looks a bit askance at her at first, then she laughs and smiles at the person. The care aide or nurse says, "She's having a good day".

1345: Then the care aide goes over to help the neighbor who is been talking to herself. The neighbor says to her, " don't try to kill me" and the nurse or care aides quickly reassures her that this is not her intent. She is there to help her with her energy drink.

The care aide says to me "Everyone is confused in this room!", as another neighbor suddenly get up from her bed and starts to walk around with her walker but in bare feet. This person appears to want to walk down the hall, but then decides to go into the bathroom.

Mrs. Ho watches the goings on in the room, rubbing her hands together at times... then she seems to drift off to sleep with her hands clasped together resting on her tray.

The care aide responds quickly to the neighbor walking in bare feet, fetching her a fresh pair of nonslip socks and brings them to her in the bathroom.

1348: Mrs. Ho drifts off to sleep in her chair, I continue to sit quietly by her side. I can hear the neighbour in the bathroom, she appears to be moaning.

1350: Mrs. Ho sleeps, the neighbor who was in bare feet has come out of the bathroom, she is moaning some more... perhaps she is in pain and constipated? She walks over to her bed and lies down at the bottom edge the bed, perpendicular to how she should be lying, leaning up against the footboard at the edge of the bed. It seems like she could fall from her bed and I go to get some help.

Two staff members come in to help her, and then a third joins them. They assist the neighbor to lie properly and safely in her bed.

Mrs. Ho has woken up with all of the activity occurring. One of the staff members comes by and interacts with her, she seems to be joking around with her and she appears to be enjoying this.

1400 hrs: Mrs. Ho is watching what is going on in the hallway through the open door...

Suddenly her mouth opens in surprise at whatever she has noticed. I can't tell what it is she has seen. She continues to watch the goings on in the hallway as I say goodbye and take my leave.

## January 15, 2020 1120 hours

Mrs. Chiang is in her room this morning, the door to her room is closed except where it is slightly ajar held open by the garbage can.

She has a private room with the sign for aggression taped up beside the doorway.

She is sitting in a chair, colouring at her bedside table.

I say hello as I enter and she waves at me and nods when I ask her if I can sit down indicating my stool. I sit down facing her.

She is attentively colouring a picture of a duck, concentrating on the duck's bill. She hands me a magazine to read when I sit down and continues to colour. There is a save-a-day tray on her bedside table with a tube of moisturizer, comb, clips and an assortment of pens and crayons in it.

At one point, she stops colouring and I try to offer her a pen, she nods but turns around in her chair and pick up a paper towel that was covering the suctioning device on the wall behind her.

She places the paper towel on her table and starts to smooth it out with her fingers.

I attempt to talk to her about what she is doing but she does not appear to notice that I am present at this point, she looks down at her picture.

1125 hours: A staff member opens the door and peeks inside the room. "Oh, you're here!" She says, smiles and then leaves.

1134 hours: Suddenly Mrs. Chiang starts to talk to me in her language, I think she is remarking on the duck picture as she is pointing out the duck's eye to me. She stops, turns the paper over and we see that there is a picture of a teddy bear on the other side. She looks at it carefully and sees that there are dried on flecks of crayon on the picture. She tries to flick them off with her finger.

The paper towel that she had been smoothing falls to the ground and she tries to pick it up but can't reach it.

I pick it up for her, she laughs and then uses it to wipe the teddy bear picture. She spends long periods of time looking at the picture, or leafing through a magazine that was also on her table. She will occasionally point something out in the magazine to me but mostly I feel that she does not notice me.

1150 hours: The lunch trays arrive and I help to set it up in front of her. She does not appear to want to eat. She shows me her watch and points at the clock in front of her on the wall. She hands me her watch and I adjust the time so that it matches the clock on the wall and she seems satisfied with this, putting her watch back on. She mostly stares at her tray when she suddenly gets up and leaves the room.

I follow her as she walks down the hall, turns the corner and heads to where her husband is sitting by the nursing station. I ask one of the nurses if Mrs. Chiang likes to wander around on her own and the nurse states that she usually leaves her room to seek out her husband. He suggests that I bring out her bedside table and lunch tray, that she likely wants to eat with her husband. So I return to her room and wheel out the table with her lunch on it.

She is standing by her husband when I arrive, but eventually sits by him and accepts her lunch tray on the table. She taps her chest, I think she wants a bib and I go to get one for her, which she happily accepts. I ask if I can sit down next to her and she assents.

Her husband has been eating his lunch and he passes her his empty plate speaking to her in their language. It seems that he wants her to place the empty plate on her tray, which she does.

She contemplates her plate and starts to speak to me. I think she wants to share her lunch with me, as she takes her fork and evenly divides the food on the plate into two portions, I think she is

offering me half. I try to decline but I think that she does not want to eat unless I take half of her food. I thank her but realize that she might not eat unless I share her lunch, which I don't feel I can do. So I decide to take my leave, thanking her and saying good bye. She takes my hand and says goodbye in English when I leave. 1220 hours

### **January 27, 2020 0900 hours**

I arrive on the ward. Two patients in stretchers are waiting in the hallway, perhaps on their way to tests or procedures.

Mr. Chiang is emerging from his room using his walker, guided by a staff member. It looks like they are going for a walk around the unit.

I enter the room. Mr. Hastings is stretched out in his bed on top of his covers. He is sound asleep, wearing his bib over his jacket, which is in turn over his PJ.

(I wonder why he isn't able to wear regular clothes?)

I see the 1:1 and Mr. Chiang walk past the room and I say hello to the 1:1.

I go to sit in the room but I close the curtain so that Mr. Hastings has privacy while he sleeps.

The 1:1 comes in to tell me that Mr. Chiang had a difficult night. According to her, they had to call security twice during the night as he was quite agitated. The 1:1 is not sure what time these incidents occurred. (I wonder what security does...do they hold him down while he is medicated?)

0910: Mr. Hastings is sleeping soundly, I can hear his deep breaths from beyond the curtain. The 1:1 has told me that Mr. Chiang has already fallen asleep in his chair out in the hallways.

0945: Mr. Hastings has been sleeping this entire time. The ward is moderately busy with rehab staff working with patients walking in the hall, patients are coming and going on stretchers, the noise has been steady but not too loud, and Mr. Hastings has slept steadily.

The 1:1 peeks in to confirm that he is still sleeping. She tells me that Mr. Chiang sleeps on as well.

0950: A lab tech suddenly comes in, pulls the curtain and wakes Mr. Hastings up for an ECG test. She chats with him easily as she sets up the monitor and the leads and runs the test.

He is awake afterwards and consents to chatting together.

10-1030 jottings. He lies on his back in the bed, his hands by his side. His hands are quite expressive as he talks.

We talk about the transition that is coming as he is leaving for facility afterwards. He is aware that he is moving and says that he is not happy about it. It is not what he wants, it is not his home. He feels that he is being sent to a care home because he is still "wobbly" when he walks. "Wobble is the way life is" he says philosophically.

We talk a bit about last night when his neighbour Mr. Chiang was awake and loud. "I think he is afraid" he says. He recognizes that Mr. Chiang likely feels restrained and that part of this is because most of the staff here cannot communicate with him.

He reflects on the decisions that are being made by others on his own behalf. "They are restricting you", he says... "the gestapo is on the move"

He says that he has "some empathy" for Mr. Chiang, when we discuss how Mr. Chiang has been feeling. We chat a bit more and I ask if I can come to say goodbye tomorrow before he leaves, he is agreeable to this. I take my leave 1030

**January 30, 2020 1340 hours**

As I enter the unit, I check in with the PCC and ask about Mr. Chiang She tells me that he likely will be in hospital for some time as it will be difficult to place him because of his behaviours. Mr. Chiang is sitting in his Broda at his usual spot by the nursing station. He is awake. I go up to say hello to him. He looked at me with blurry looking eyes and does not smile. He mutters something to me in his own language. I do not feel that he is giving me assent to sit next to him. I go to sit by the clinical educator's office to observe.

He has a magazine on his tray and a Chinese video is playing on an iPad that is set up on the rolling bedside table that has been placed in front of him. He has his knit cap and glasses on. I can't tell if he is wearing his TED stockings today, perhaps they are on under his hospital socks? He seems to have a cold, his nose is running and he is coughing a bit. He spends some time fidgeting with the zipper on his down vest that he is wearing over his PJs. He examines the zipper for several minutes. He then simply stares down at his magazine until he falls asleep around 1350 hours. The clinical educator mentions to me that he has been quite drowsy.

1355: A staff person comes by and turns off the iPad and reclines his chair, putting a pillow behind his head so that he is more comfortable.

1400-1430: He continues to sleep deeply. He does not rouse despite afternoon activity on the ward going on around him. The CST team comes by. For several minutes there are several people and equipment right by him. There is conversation as the CST team prepares to take a tour of the ward. He does not wake.

I wonder if it a medicated or sleep reversal slumber I am seeing?

Portrait of sleeping:

He is reclined in a special chair, slightly leaning to the Right side, his head supported by a pillow. His feet twitch slightly in his sleep, resting on the chair's footrests. He is sleeping deeply, mouth slightly pursed, lips vibrating slightly with each exclamation. He does not rouse when people walk by or when the noise of the unit rises around him.

He is almost like a person having a nap in an armchair at home, but not....

1500: The care aide who often cares for Mr. Chiang and speaks his language comes on shift. She tells me that Mr. Chiang was having some difficulties yesterday afternoon and evening. He was very restless and would not stay in bed. She tells me that at one point he wanted to get up and go to boil water to wash himself and was very difficult to settle. She was saying that on past occasions, he could be more easily settled and redirected, especially with an offer of a snack, but that this is not as successful a strategy anymore. She tells me that he wants the tray of his Broda chair off and despite her ability to communicate with her in his language, it is hard for him to understand why the tray needs to stay on.

1530: He has been sleeping non-stop, he has not moved. He suddenly coughs, clears his throat and moves his head a bit but does not open his eyes, keeps sleeping.

1532: yawns a few times, I wonder if he is going to wake up soon.

I keep observing, he does not wake. I take my leave at 1610 hours, he has not woken up.

## **Appendix E: Interview Guide for Patient Participants**

1. Can you tell me about what it has been like to be in hospital?
2. What has changed for you during your stay in hospital?
3. Are you familiar with the term “Alternate Level of Care”?

What has this meant for you?

4. What is a “good day” in the hospital like for you?
5. What happens when you have a “bad day”?
6. What has been helpful for you during your hospitalization?
7. How do you think your care could be improved?



## Appendix F: Consent Form (Patients)

### Consent Form: Patient Participants

#### Dementia and the Alternate Level of Care Experience

**Principal Investigator:** **Dr. Alison Phinney, RN, PhD**  
Professor, School of Nursing  
University of British Columbia



**Co-investigators:** **Mariko Sakamoto, RN, PhD Candidate**  
School of Nursing  
University of British Columbia



**Dr. Jennifer Baumbusch, RN, PhD**  
Associate Professor  
School of Nursing  
University of British Columbia



**Dr. Genevieve Thompson, RN, PhD**  
Associate Professor  
College of Nursing  
University of Manitoba



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You are being invited to participate in this research study because you have been identified by your health care team at the hospital as someone who is appropriate for this study.

This form explains the consent that is needed from you to participate in the study, if you decide that you are interested in participating.

Mariko Sakamoto is conducting this research for her doctoral dissertation in the School of Nursing PhD program at the University of British Columbia. This research will result in the publication of a dissertation that will be publicly available.

**Purpose of the Study:** The purpose of this study is to explore the care experiences of Alternate Level of Care (ALC) patients with dementia who are currently hospitalized. We believe that this research is important, as it will provide important information about how we can provide the best possible supports and care for patients in hospital. Findings from this study will be shared with patients and family members, policy-makers, administrators, health care decision-makers and educators to inform and improve care.

**Study Participation:** If you consent to participate in the study, this will involve:

- **Observation of activity** you take part in while hospitalized. This observation time could include time spent alone or in activities, as well as interactions with care staff (e.g. nurses), volunteers, family and other visitors. The researcher (Mariko) will spend up to two hours at a time of direct observation (e.g. sitting next to you, spending time in the hospital room) and will not interfere with usual hospital routines. Observations will start from the time of consent and will conclude once a maximum of 12 hours of observation is reached. The researcher will continually check with you, as well as family and visitors to ensure that observations are not intrusive. Notes about the nature of the activities and interactions including responses by you, family and visitors will be written down.
- **Observations of your personal care** such as personal hygiene routines and dressing. Consent is being sought to observe **select** personal care situations. Personal care situations could include intimate care such as bathing, showering, and toileting, but only if I have provided consent. If the personal care taking place is of a more sensitive nature, in addition to ensuring that I am comfortable with the researcher's presence in the room, the researcher would place herself nearby but out of sight, and in doing so would be protecting the participant's dignity. The specific personal care interactions to be observed will be negotiated between yourself and staff members. The researcher will ensure that your dignity is not compromised and will remove herself from the situation if you become uncomfortable by her presence. Notes about the observation period will be written down.
- **An Interview** may take place if you are willing to take part in one. This would involve the researcher asking you about what it is like being an ALC patient. The interview could take anywhere from 30-90 minutes and would be audiotaped. If an interview is not possible or suitable, the researcher will engage in **informal conversations** with you. Informal conversations may last anywhere from 5-30 minutes. Notes will be taken about the nature of the interaction and responses of conversations. Informal conversations could also take place with hospital staff and visitors during these times, and every effort will be made to include you in these conversations. At times, if you are willing and the opportunity arises, the researcher might audiotape conversations that occur.

- The researcher's attendance at patient conferences or meetings regarding your care.
- The researcher's access to documents related to you such as the medical chart and Kardex and could include: admission information, demographic information and date of ALC designation.

**Possible Risks:** Due to the presence of the researcher, you may feel anxious or upset during periods of observation or conversation. Special care will be taken to ensure that the researcher's presence does not upset you or make you feel uncomfortable. If at any time during observations or interactions, should you feel uncomfortable, anxious or upset by the researcher's presence, she will stop observation and/or conversation immediately and leave. If you decide that you no longer want to participate in observations, you will be asked if any data that has been collected up to that point can be included in the study results.

In terms of patient observation periods, some of which might include personal care routines, there is the potential for loss of privacy. The researcher will take great care, and situations where your dignity might be compromised will not be observed. The researcher will assess all situations as they arise, check that they are okay with you and remain respectful and sensitive to you at all times.

**Potential Benefits:** By participating in this study, you will help health care professionals understand patients' care experiences better, which will provide important information on how to improve care for ALC patients living with dementia. Overall, very little is known about the daily hospital experiences of ALC patients living with dementia. Participation in this study will mean that you will be contributing to increased knowledge about this particular health care experience.

**Maintaining Confidentiality:** The researcher will make every effort to keep your information private and confidential. No real names will appear in the notes or written reports (only code names will be used) and any identifying information will be removed. The researcher will check with you when it comes to documenting and sharing sensitive information. In addition, you will be given the opportunity to review interpretation of collected data.

All notes, documents and recordings will be identified by a code number and will be kept in a locked filing cabinet in the researcher's home office and any electronic data will be kept on a password-protected computer and encrypted USB drive. Consent form will be kept in a separate locked cabinet. Only the researcher and member of her dissertation committee will have access to the information.

**Sharing of Study Results:** The results of the study will be reported in a doctoral dissertation, published in relevant academic journals and presented at scientific conferences and public presentations. Results will be shared with other academics, health care professionals, students and the wider public. Results will also be shared with you.

**Storing of Collected Data:** Data will be retained for up to five years following the study. During this time, the data may be re-analyzed to answer other research questions related to the experience of being an ALC patient with dementia in hospital. Data may also be used for educational purposes. Only the researcher will have access to the stored raw data.

**Contact Information:** If you have any questions regarding any aspect of this study, please contact Mariko Sakamoto at [REDACTED] or Dr. Alison Phinney at [REDACTED].

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

**Consent and Signatures:** Your participation in this study is entirely voluntary. If you do not wish to participate, you do not have to provide a reason. Your decision will in no way influence or affect the care and services you receive. If you do decide to participate, and then change your mind, you are free to withdraw them from the study at any time and do not need to provide a reason. Should you withdraw them from the study, you will be asked at that time whether previously collected data can be used in the analysis, or whether you prefer that it be deleted.

Your signature below indicates that:

- You understand the conditions of participation above
- You have had the opportunity to have your questions answered
- You have received a copy of this consent form for your records
- You consent to participating in the study

Name of Participant: \_\_\_\_\_

Participant #: \_\_\_\_\_

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Signature of participant

Date

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Printed name of participant

Date



## Appendix G: Consent Form (Representative)

### Consent Form: Representative/Temporary Decision Maker

#### Dementia and the Alternate Level of Care Experience

**Principal Investigator:** **Dr. Alison Phinney, RN, PhD**  
Professor, School of Nursing  
University of British Columbia



**Co-investigators:** **Mariko Sakamoto, RN, PhD Candidate**  
School of Nursing  
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**Dr. Jennifer Baumbusch, RN, PhD**  
Associate Professor  
School of Nursing  
University of British Columbia



**Dr. Genevieve Thompson, RN, PhD**  
Associate Professor  
College of Nursing  
University of Manitoba



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Your family member is being invited to participate in this research study because [he/she] has been identified by the Patient Care Coordinator/Social Worker as being an appropriate participant for this study.

Your consent is being sought for your family member's participation as you have been identified as the main contact person and substitute decision maker.

This research is being conducted as part of Mariko Sakamoto's doctoral requirements in the School of Nursing PhD program at the University of British Columbia. This research will result in the publication of a dissertation that will be publicly available.

**Purpose of the Study:** The purpose of this study is to explore the care experiences of Alternate Level of Care (ALC) patients with dementia who are currently hospitalized. We believe that this research is important, as it will provide valuable insights into how we can provide the best possible supports and care for this population of hospital patients. Findings from this study will be shared with patients and family members, health care professionals, policy-makers, administrators, health care decision-makers and educators to inform dementia and ALC care policy and practice.

**Study Participation:** If you consent that [patient's name] can participate in the study, this will involve:

- **Observation of [participant's name] activity** while designated ALC and hospitalized. This observation time could include time spent alone or in activities, as well as interactions with care staff (e.g. nurses), volunteers, family and other visitors. The researcher (Mariko) will spend up to two hours at a time of direct observation (e.g. sitting next to him or her, spending time in the hospital room) and will not interfere with usual hospital routines. Observations will commence at the time of consent and will conclude once a maximum of 12 hours of observation is reached. The researcher will continually check with the participant, family and visitors to ensure that observations are not intrusive. Notes about the nature of the activities and interactions including responses by the participant, family and visitors will be written down.
- **Observations of [participant's name] personal care** such as personal hygiene routines and dressing. Consent is being sought to observe **select** personal care situations. Personal care situations could include intimate care such as bathing, showering, and toileting, but only if the patient participant has provided assent. If the personal care taking place is of a more sensitive nature, in addition to ensuring that the participant is comfortable with the researcher's presence in the room, the researcher would place herself nearby but out of sight, and in doing so would be protecting the participant's dignity. The specific personal care interactions to be observed will be negotiated between yourself, the staff member and [participant's name]. The researcher will ensure that the dignity of [participant's name] is not compromised and will remove herself from the situation if [participant's name] is distressed by her presence. Notes about the observation period will be written down.
- **An Interview** may take place if [participant's name] is able to take part in one. This would involve the researcher asking [participant's name] about what it is like being an ALC patient. The interview could take anywhere from 30-90 minutes and would be

audiotaped. If an interview is not possible, the researcher will engage in **informal conversations** with [participant's name]. Informal conversations may last anywhere from 5-30 minutes. Notes will be taken about the nature of the interaction and responses of conversations. Informal conversations could also take place with hospital staff and visitors during these times, and every effort will be made to include [participant's name] in these conversations. At times, if [participant's name] is willing and the opportunity arises, the researcher might audiotape conversations that occur one on one with your family member.

- The researcher's attendance at patient conferences or meetings regarding [participant's name] care.
- The researcher's access to documents related to [participant's name] such as the medical chart and Kardex and could include: admission information, demographic information and date of ALC designation.

**Analysis of Data:** The researcher will be analyzing the observations notes, interview transcript and notes of informal conversations in an effort to understand and describe the experience of your family member as an ALC patient living with dementia. These will be read and analyzed along with others to see if there are similarities and differences in experiences. The researcher may also be using excerpts from her field notes and from the interview transcript to compose found poetry, as part of an arts-based research approach.

**Possible Risks:** Due to the presence of the researcher, [participant's name] may feel anxious or upset during periods of observation or conversation. Special care will be taken to ensure that the researcher's presence does not upset the participant. If at any time during observations or interactions, should [participant's name] appear anxious or upset by the researcher's presence, she will stop observation and/or conversation immediately and leave. If the participant repeatedly expresses concern or seems upset by the researcher's presence, you will be contacted and the participant will be removed from the study. If that should occur, you will be asked if any data that has been collected up to that point can be included in the study results.

In terms of patient observation periods, some of which might include personal care routines, there is the potential for loss of privacy. The researcher will take great care, and situations where the dignity of the participant might be compromised will not be observed. The researcher will assess all situations as they arise and remain respectful and sensitive to [participant's name] at all times.

**Potential Benefits:** By participating in this study, [participant's name] will help health care professionals understand his/her care experiences better, which will provide important information on how to improve care for ALC patients living with dementia. Overall, very little is known about the daily hospital experiences of ALC patients living with dementia. Participation

in this study will mean that [participant's name] will be contributing to increased knowledge about this particular health care experience.

**Maintaining Confidentiality:** The researcher will make every effort to keep [participant's name] information private and confidential. No real names will appear in the notes or written reports (only code names will be used) and any identifying information will be removed. The researcher will check with you when it comes to documenting and sharing sensitive information. In addition, as [participant's name] representative, you will be given the opportunity to review interpretation of collected data.

All notes, documents and recordings will be identified by a code number and will be kept in a locked filing cabinet in the researcher's home office and any electronic data will be kept on a password-protected computer and encrypted USB drive. Consent form will be kept in a separate locked cabinet. Only the researcher and member of her dissertation committee will have access to the information.

**Sharing of Study Results:** The results of the study will be reported in a doctoral dissertation, published in relevant academic journals and presented at scientific conferences and public presentations. Results will be shared with other academics, health care professionals, students and the wider public. Results will also be shared with you.

**Storing of Collected Data:** Data will be retained for up to five years following the study. During this time, the data may be re-analyzed to answer other research questions related to the experience of being an ALC patient with dementia in hospital. Data may also be used for educational purposes. Only the researcher will have access to the stored raw data.

**Contact Information:** If you have any questions regarding any aspect of this study, please contact Mariko Sakamoto at [REDACTED] or Dr. Alison Phinney at [REDACTED].

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

**Consent and Signatures:** Your family member's participation in this study is entirely voluntary. If you do not wish for them to participate, you do not have to provide a reason. Your decision will in no way influence or affect the care and services they receive. If you do decide to have them participate, and then change your mind, you are free to withdraw them from the study at any time and do not need to provide a reason. Should you withdraw them from the study, you will be asked at that time whether previously collected data can be used in the analysis, or whether you prefer that it be deleted.

Your signature below indicates that:

- You understand the conditions of participation above
- You have had the opportunity to have your questions answered
- You have received a copy of this consent form for your records

- You consent to your family member's participation in the study

Name of Participant: \_\_\_\_\_

Participant #: \_\_\_\_\_

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Signature of representative/substitute decision maker

Date

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Printed name of representative/substitute decision maker

Date

## Appendix H: Assent Form



### Assent Form: Patient Participants

#### Dementia and the Alternate Level of Care Experience

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I am being invited to participate in a research study. The research study is trying to find better ways to care for people living with dementia who are in the hospital and who are called Alternate Level of Care patients. It is up to me if I want to be in this study. Even if I agree now to be part of the study, I can change my mind later. There will not be any problems if I choose not to be a part of this study.

#### Why Are We Doing This Study?

I am a person living with dementia. I am also in the hospital and am an Alternate Level of Care patient. This study is trying to understand what it is like to be an Alternate Level of Care patient who is also living with dementia. This study will help health care teams learn more about people like me who are in the hospital and help them to provide the best care possible.

#### What Will Happen in This Study?

If I agree to be in this study, the researcher will come and spend time with me while I am in the hospital. She will spend up to two hours with me during different times of the day. She will only spend a total of twelve hours with me.

The researcher will be watching when I receive care from the health care team, when I visit with family and talk to people on the hospital unit. She will also spend time talking with me, asking me how I am doing and what I am thinking. The researcher may sit down with me for a formal interview if I feel like it. If I do agree to an interview, she will audio record our interview.

The researcher will only spend time with me if I am okay with that and she will leave if I do not feel like having her around. The researcher will be respectful of me and will not spend time with me while I am receiving certain kinds of care like when I am getting a bath or a shower.

The researcher will also look at my hospital chart to find out information about when I came to the hospital and when I became an Alternate Level of Care patient, and will attend patient care meetings about my care.

#### Who is Doing This Study?

Dr. Alison Phinney is a registered nurse and a Professor of Nursing at the University of British Columbia. She is leading this study. Her student, Mariko Sakamoto, will be the researcher spending time with me and talking to me. Mariko is a PhD student and is also a registered nurse. Dr. Phinney and Mariko will answer any questions I have about the study. I can also call them at [REDACTED] if I have any questions or am having any problems.

**Can Anything Bad Happen to Me?**

There is nothing in the study that can cause any physical harm to me. I might feel uncomfortable when Mariko is spending time with me. I might also feel sad or upset when talking about being a hospital patient. If I am uncomfortable, or feeling sad or upset, I can ask Mariko to leave and come talk to me later. I can also ask Mariko to not come talk to me or spend time with anymore if I feel like it.

**Who Will Know I Am in the Study?**

Only Dr. Phinney, Mariko and two other professors who are helping Mariko will know I am in the study. The two other professors are Dr. Jennifer Baumbusch and Dr. Genevieve Thompson. My family members also will know that I am in the study. When the study is finished, Mariko will write a report about what was learned. This report will not say my name or that I was in the study.

**When Do I Have to Decide?**

I have as much time as I want to decide to be a part of the study. I have also been asked to discuss my decision with my family members.

**Assent**

If I tell the researcher that I am willing to be in the study, she will write down that I have agreed to be in this study.

Date of recorded assent: \_\_\_\_\_

## **Appendix I: Interview Guide for Family Caregivers**

1. How would you describe your family member's experience during their hospitalization?
2. Are you familiar with the term "Alternate Level of Care" or "ALC"? What has this designation meant for your family member?
3. How would you describe the care that your family member has received as an ALC patient?
4. Can you describe a "good day" for your family member? What is a "bad day" like?
5. What has changed for your family member during their hospitalization?
6. What has been helpful for your family member during their hospitalization?
7. How do you think care for your family member could be improved?

## Appendix J: Consent Form (Family)



### Consent Form: Family Members

**Title: Dementia and the Alternate Level of Care Experience**

**Principal Investigator:** **Dr. Alison Phinney, RN, PhD**  
Professor, School of Nursing  
University of British Columbia



**Co-investigators:** **Mariko Sakamoto, RN, PhD Candidate**  
School of Nursing  
University of British Columbia



**Dr. Jennifer Baumbusch, RN, PhD**  
Associate Professor  
School of Nursing  
University of British Columbia



**Dr. Genevieve Thompson, RN, PhD**  
Associate Professor  
College of Nursing  
University of Manitoba



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You are being invited to participate in this research study because you are a family member of an ALC patient living with dementia who has been hospitalized. Your consent is being sought to participate in this study.

This research is being conducted as part of Mariko Sakamoto's doctoral requirements in the School of Nursing PhD program and the University of British Columbia. This research will result in the publication of a dissertation that will be publicly available.

**Purpose of the Study:** The purpose of this study is to explore the care experiences of Alternate Level of Care (ALC) patients with dementia who are currently hospitalized. As a family member, you have valuable knowledge about the experiences of these patients. We believe that

this research is important, as it will provide valuable insights into how we can provide the best possible supports and care for this population of hospital patients. Findings from this study will be shared with policy-makers, administrators, health care decision-makers and educators to inform dementia and ALC care policy and practice.

**Study Participation:** If you consent to participate in the study, this will involve:

- **One-on-One Interview:** The researcher (Mariko) will interview you by asking you a few questions about your family member's experiences as an ALC patient with dementia. The interview will likely last anywhere from 30-90 minutes and will take place in a location of your choosing. The interview will be audiotaped and the recordings will be transcribed into text. I will use the text to try to understand the hospital care experience of your family member as an ALC patient living with dementia. Your interview will be read and analyzed along with others to see if there are similarities and differences in experiences. The researcher may also be using excerpts from your interview transcript to compose found poetry, as part of an arts-based research approach.

**Possible Risks:** While there are no anticipated risks of participating in this study, there is the possibility that talking about your family member's experiences could make you feel upset. If this happens, please feel free to tell the researcher. If talking about your family member's experiences becomes difficult, time can be taken for you to gather your thoughts and you can return to the interview when you feel ready. If at any time you feel that you would like to stop, the interview can be immediately halted and taken up on another occasion. If you do not want to continue all together, you can ask to be removed from the study. If that should occur, you will be asked if any data that has been collected up to that point can be included in the study results.

**Potential Benefits:** By participating in this study, you will help health care professionals better understand the care experiences of ALC patients living with dementia, which will provide important information on how to improve these patients' care. Overall, very little is known about the daily hospital experiences of ALC patients living with dementia. Participation in this study will mean that you will be contributing to increased knowledge about this particular health care experience. You may also experience a sense of satisfaction in offering your unique point of view as part of this study.

**Maintaining Confidentiality:** The transcript from your interview will be identified by a number and your name will not appear on it. The researcher will make every effort to keep your information private and confidential. No real names will appear in the notes or written reports (only code names will be used) and any identifying information will be removed. In addition, as a study participant, you will be given the opportunity to review interpretation of collected data.

All notes, documents and recordings will be identified by a code number and will be kept in a locked filing cabinet in the researcher's home office and any electronic data will be kept on a password-protected computer and encrypted USB drive. Consent forms will be kept in a separate locked cabinet. Only the researcher and member of her dissertation committee will have access to the information.

**Sharing of Study Results:** The results of the study will be reported in a doctoral dissertation, published in relevant academic journals and presented at scientific conferences and public presentations. Results will be shared with other academics, health care professionals, students and the wider public. Results will also be shared with you.

**Storing of Collected Data:** Data will be retained for up to five years following the study. During this time, the data may be re-analyzed to answer other research questions related to the experience of being an ALC patient with dementia in hospital. Data may also be used for educational purposes. Only the researcher will have access to the stored raw data.

**Contact Information:** If you have any questions regarding any aspect of this study, please contact Mariko Sakamoto at [REDACTED] or Dr. Alison Phinney at [REDACTED].

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

**Consent and Signatures:** Your participation in this study is entirely voluntary. If you do not wish to participate, you do not have to provide a reason. Your decision will in no way influence or affect the care and services your family member receives. If you do decide to participate, and then change your mind, you are free to withdraw from the study at any time and do not need to provide a reason. Should you withdraw from the study, you will be asked at that time whether previously collected data can be used in the analysis, or whether you prefer that it be deleted.

Your signature below indicates that:

- You understand the conditions of participation above
- You have had the opportunity to have your questions answered
- You have received a copy of this consent form for your records
- You consent to participating in the study

Printed Name of Participant: \_\_\_\_\_

Participant #: \_\_\_\_\_

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Signature of participant

Date

## Appendix K: Consent Form (Nurses)



### Consent Form: Health Care Professionals

**Title: Dementia and the Alternate Level of Care Experience**

**Principal Investigator:** **Dr. Alison Phinney, RN, PhD**  
Professor, School of Nursing  
University of British Columbia



**Co-investigators:** **Mariko Sakamoto, RN, PhD Candidate**  
School of Nursing  
University of British Columbia



**Dr. Jennifer Baumbusch, RN, PhD**  
Associate Professor  
School of Nursing  
University of British Columbia



**Dr. Genevieve Thompson, RN, PhD**  
Associate Professor  
College of Nursing  
University of Manitoba



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You are being invited to participate in this research study because you are a hospital employee and health care professional involved in the care of ALC patients living with dementia. Your consent is being sought to participate in this study.

This research is being conducted as part of Mariko Sakamoto's doctoral requirements in the School of Nursing PhD program and the University of British Columbia. This research will result in the publication of a dissertation that will be publicly available.

**Purpose of the Study:** The purpose of this study is to explore the care experiences of Alternate Level of Care (ALC) patients with dementia who are currently hospitalized. As a health care professional who routinely is involved in the care of this patient population, you have valuable knowledge that you could share about these patients' hospital experiences. We believe that this

research is important, as it will provide valuable insights into how we can provide the best possible supports and care for this population of hospital patients. Findings from this study will be shared with patients and family members, health care professionals, policy-makers, administrators, health care decision-makers and educators to inform dementia and ALC care policy and practice.

**Study Participation:** If you consent to participate in the study, this will involve:

- **One-on-One Interview:** The researcher (Mariko) will interview you by asking you a few questions about the hospital care of ALC patients with dementia. The interview will likely last anywhere from 30-90 minutes. The interview will be audiotaped and the recordings will be transcribed into text. The researcher will use the text to try to understand the hospital care experiences of ALC patients living with dementia. Your interview will be read and analyzed along with others to see if there are similarities and differences. The researcher may also be using excerpts from your interview transcript to compose found poetry, as part of an arts-based research approach.

**Possible Risks:** While there are no anticipated risks of participating in this study, there is the possibility that talking about patient experiences could make you feel uncomfortable or upset. If this happens, please feel free to tell the researcher. If at any time you feel that you would like to stop, the interview can be immediately halted and taken up on another occasion. If you do not want to continue, you can ask to be removed from the study. If that should occur, you will be asked if any data that has been collected up to that point can be included in the study results.

**Potential Benefits:** By participating in this study, you will help other health care professionals, as well as policy makers, better understand the care experiences of ALC patients living with dementia, which will provide important information on how to improve these patients' care. Overall, very little is known about the daily hospital experience of ALC patients living with dementia. Participation in this study will mean that you will be contributing to increased knowledge about this particular health care experience. You may also experience a sense of satisfaction in offering your unique point of view as part of this study.

**Maintaining Confidentiality:** The transcript from your interview will be identified by a number and your name will not appear on it. The researcher will make every effort to keep your information private and confidential. No real names will appear in written reports (only code names will be used) and any identifying information will be removed. The fact of your participation will not be shared with your employer or fellow employees. In addition, as a study participant, you will be given the opportunity to review interpretation of collected data.

All notes, documents and recordings will be identified by a code number and will be kept in a locked filing cabinet in the researcher's home office and any electronic data will be kept on a password-protected computer and encrypted USB drive. Consent form will be kept in a separate locked cabinet. Only the researcher and member of her dissertation committee will have access to the information.

**Sharing of Study Results:** The results of the study will be reported in a doctoral dissertation, published in relevant academic journals and presented at scientific conferences and public presentations. Results will be shared with other academics, health care professionals, students and the wider public. Results will also be shared with you.

**Storing of Collected Data:** Data will be retained for up to five years following the study. During this time, the data may be re-analyzed to answer other research questions related to the experience of being an ALC patient with dementia in hospital. Data may also be used for educational purposes. Only the researcher will have access to the stored data long-term.

**Contact Information:** If you have any questions regarding any aspect of this study, please contact Mariko Sakamoto at [REDACTED] or Dr. Alison Phinney at [REDACTED].

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or call toll free 1-877-822-8598.

**Consent and Signatures:** Your participation in this study is entirely voluntary. If you do not wish to participate, you do not have to provide a reason. Your decision will in no way influence or affect your employment status or standing with the health authority. If you do decide to participate, and then change your mind, you are free to withdraw from the study at any time and do not need to provide a reason. Should you withdraw from the study, you will be asked at that time whether previously collected data can be used in the analysis, or whether you prefer that it be deleted.

Your signature below indicates that:

- You understand the conditions of participation above
- You have had the opportunity to have your questions answered
- You have received a copy of this consent form for your records
- You consent to your family member's participation in the study

Printed Name of Participant: \_\_\_\_\_

Participant #: \_\_\_\_\_

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Signature of participant

Date

---

Printed name of participant

Date

## **Appendix L: Interview Guide for Nurses**

1. What do you think it is like for ALC patients with dementia to be hospitalized?
2. How would you describe the care that ALC patients with dementia receive while in hospital?
3. How would you describe “good care” for ALC patients with dementia?
4. What are some of the challenges you’ve encountered or noticed while caring for ALC patients with dementia?
5. How do you think care for ALC patients with dementia could be improved?

## Appendix M: Researcher Poster

# NOTICE TO ALL STAFF AND VISITORS

As part of her PhD dissertation, **researcher Mariko Sakamoto** will be **observing and recording the daily routines** surrounding care for patients living with **dementia** with an **Alternate Level of Care (ALC) designation**.

Recordings of general observations of patients, family members/visitors, and staff who have not consented to an interview or to more intimate observation will not include any personal identifiers.

This research will uncover crucial information about how we can provide the best possible supports and care for ALC patients living with dementia and findings will be extended to those who carry the ability to improve care.

If you have any further questions, Mariko will be wearing a name-tag when she is on the ward or you can email her at [REDACTED]

Ethics ID H18-03337 May 10, 2019



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## Appendix N: ALC Codes\*

ALC code	Category of Care
<b>AL0</b>	Awaiting Residential Care: Assessed & Ready to Go (ARTG) as confirmed by TST
<b>AL1</b>	Awaiting Assisted Living/Supportive Housing
<b>AL2</b>	Awaiting Transitional Care Unit/Supportive Housing
<b>AL3</b>	Awaiting Hospice
<b>AL4</b>	Awaiting Home Health
<b>AL5</b>	Awaiting Specialized/Tertiary Mental Health & Addiction Services
<b>AL6</b>	Awaiting Mental Health & Addiction Community Services
<b>AL7</b>	Awaiting Adequate Housing
<b>AL8</b>	Awaiting Family or Social Services
<b>AL9</b>	Awaiting Specialized Rehabilitation Services
<b>AL10</b>	Assessment in Progress – Residential Care
<b>AL11</b>	Assessment in Progress-Other

\* Adapted from *Definitions and Guidelines to Support ALC Designation in Acute Inpatient Care (CIHI, 2018)*