The Aching Backbone: Perceptions and experiences of care aides in long-term residential care

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Abstract

Purpose: Care aides provide most of the direct care for residents in long-term residential care (LTRC), and thus hold the greatest potential to improve residents' quality of life. Two-thirds of residents in these facilities are older adults with dementia. The number of care aides working in LTRC needed to support Canada's aging population is only expected to increase with time. Like residents in LTRC, care aides are a disenfranchised population. There is little understanding of what are the experiences and perceptions of care aides in LTRC. This doctoral thesis adds to the scarce body of knowledge that sheds light on the experience of care aides in LTRC. This study was informed by the literature on person-centered care and personhood theory, as well as critical gerontology and institutional theory. The purpose of this study was to understand the experiences and perceptions held by care aides in LTRC and to identify their perceived barriers and facilitators toward the delivery of care to residents.

Method: The overall methodology for this study was a qualitative design, using ethnographic data-generating methods from one complex-care floor located within a campus of care facility in rural and remote Western Canada. Data sources for this study included the following: semi-structured interviews (70 hours) with 31 care aides, naturalistic observation (170 hours), and reflexive journaling (20,000 words). Thematic analysis was used to examine all data sources.

Results: Care aides' experiences entering and working in LTRC are varied; however, there are common overarching themes, including not being adequately trained for the realities of working as care providers and the scope of practice they are expected to fulfill within LTRC, as well as being under supported in their role. Participants report strong feelings of responsibility and affection for their residents, yet they perceive insurmountable barriers in their role that prevent them from delivering the care they would like to give. These barriers include the following: (i) lack of standardized education and training; (ii) lack of proper equipment; (iii) lack of autonomy over their residents; (iv) politics and bullying within the power hierarchy of LTRC; and (v) chronic unaddressed moral distress among care aides. Suggestions for improvement of care delivery in LTRC include the following: (i) standardization of care aide education and training; (ii) incorporation of reporting measures specifically for care aides; and (iii) increased autonomy of care aides over their residents.

Implications: The support and empowerment of care aides in LTRC are fundamental in the delivery of good care to residents. Care aides have expressed that their attitudes toward their job are low because they feel unheard and voiceless within their work environment. Efforts to empower care aides' voices should be developed and implemented to meet the needs of a large segment of Canada's population living with dementia—residents in LTRC.

Keywords: care aides, healthcare aides, personal support worker, dementia, qualitative research, long-term care, person-centered care

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Table of Contents

List of Tables

List of Figures

Chapter 1. Introduction and Overview

1.1. Purpose of Research

Canada's 2016 census states that by 2035 the nation will join the ranks of super-aged countries, meaning that more than 30% of its entire population will be older than age 60 (Statistics Canada, 2017a). Similarly, 2015 marked a pivotal milestone for Canada as the first time in the nation's history that the number of people age 65 and older surpassed the number of those ages 15 and younger. In addition, the number of Canadians who are age 85 or older, the "oldest old," is seeing an unprecedented boom. This has never been seen before and the pace at which the number of older adults in Canada is growing is predicted not to slow down anytime soon. Currently, the overall life expectancy for Canadian women has reached 83 years and for men 79 years (Statistics Canada, 2017a). Unfortunately, the healthy life expectancy has not increased at the same pace. An increase in predicted longevity is not seen to always correlate with an increase in health. In fact, more than 30% of the oldest old in Canada have three or more chronic illnesses, with dementia as the most feared health condition related to aging (Muir, 2017). With a rapidly aging population, the increase in the number of cases of dementia in Canada results in a significant financial cost and places enormous pressure on the current state of Canada's healthcare system- especially long-term residential care (LTRC).

1.1.1. The Increasing Importance of Long-Term Residential Care

Long-term residential care (LTRC) continues to remain one of the most important features of a developed nation's healthcare systems. In 2016, the healthcare and social assistance industry in Canada was the largest employer among all industries with just more than 2 million people, which represents 12.1% of all workers (Government of Canada, 2017). As in previous census, women outnumbered men four to one in health occupations, with employment as a care aide the eighth most common occupation for women in Canada (Government of Canada, 2017).

The LTRC sector currently cares for nearly 4% of the Canadian population above the age of 65 (Muir, 2017; Office of the Seniors Advocate [OSA], 2016). Over a quarter of a million people age 85 and older live in collective dwellings such as nursing homes, LTRC facilities, and seniors' residences. This means that nearly one in three people age 85 and older live in one of these three forms of collective dwellings (Statistics Canada, 2017c). In 2016, nearly 500'000 Canadians, or 1.2% of the entire population, were recorded as living in nursing homes or residences for senior citizens (Statistics Canada, 2017c). Since 2011, it has also been reported that the population age 85 and older living in collective dwellings has grown by a staggering 23.0%, compared with an overall growth rate of 19.4% for the total population age 85 and older. This means that nearly half of the people age 85 and older living in collective dwellings in 2016 were between the ages of 85 and 89 (Statistics Canada, 2017b). Moreover, three-quarters of residents in collective dwellings age 85 and older were women, and the number of women increases to 86.1% among centenarians (Statistics Canada, 2017a). Given these reported statistics on the state of the aging population, communal living arrangements, such as LTRCs, can be expected to continue to grow in the future (Statistics Canada, 2017c). Along with a growing need for LTRC services will be an increased requirement for adequate dementia care services. The following section will review the relationship between Canada's aging population and dementia care needs.

1.1.2. Dementia and an Aging Population

Along with an aging population is an increase in the rates of dementia (Wong, Gilmour, & Ramage-Morin, 20162016). Dementia has been called the "disease of the century" (Leibing & Cohen, 2006, p. 250), with an estimated 46.8 million people currently living with dementia worldwide (Alzheimer's Disease International [ADI], 2015). The total estimated worldwide costs of dementia (direct costs such as medical and social care, and indirect costs such as unpaid caregiving by families and friends) are $645 US billion per year (Organisation for Economic Co-operation and Development [OECD], 2015). With an ageing population, these costs are also expected to increase substantially.

Globally, dementia is already the second-largest cause of disability for people over the age of 70 (OECD, 2015). In Canada, the number of individuals living with dementia is currently around 564’000, with projections indicating that this number will double every 15 years to 20 years (Wong, Gilmour, & Ramage-Morin, 2016). Alzheimer’s Disease International (2015) predicts that the number of persons living with dementia by 2030 will increase to 75 million.

Dementia does not affect both genders equally. Just as there are a greater number of women among the 65 and older population, there are proportionally more women living with dementia, whether in LTRC or home-based settings (Wong, Gilmour, & Ramage-Morin, 2016). It has been well documented in the dementia discourse that caring for an individual with dementia may be overwhelming both for family members as well as for formal care partners (Frank, 2009; McCabe, You, & Tatangelo, 2016; Wong, Gilmour, & Ramage-Morin, 2016). The impact on care partners, families, and society can be physical, psychological, social, and economic (Frankish & Horton, 2017). Understandably, it is common that older persons with dementia want to remain in their own homes and age in place in the community for as long as they can to preserve their individual personhood, quality of life, and independence (Chen, Thompson, Berkowitz, Young, & Ward, 2011; Cloutier, Penning, Nuernberger, Taylor, & MacDonald, 2017). Nonetheless, for some individuals the complexities of dementia (e.g., type of dementia or rate of progression) and the limitations on family care partner supports may result in needing to access LTRC services (Callahan et al., 2015; Cloutier, Penning, Nuernberger, Taylor, & MacDonald, 2017; Manderson, Mcmurray, Piraino, & Stolee, 2012).

As persons with dementia progress through the disease trajectory, the amount of care required will increase and most likely consist of 24-hour nursing care provided by an LTRC (ASO, 2016). A significant proportion of older adults receiving care across residential care settings will be living with dementia. The rates of dementia and specialized care needed in LTRC settings have already radically increased over the past two decades and will continue to increase as the population ages (Swartz, Miake, & Farag, 2012). The current number of residents living in LTRC in Canada who have a diagnosis of dementia is not agreed upon; some estimate 45% (Wong, Gilmour, & Ramage-Morin, 2016), while others say upwards of 61% (OSA, 2016). Neither estimation may accurately represent the true picture of people living with dementia in LTRC because many residents with dementia will not have received a formal diagnosis (Frankish & Horton, 2017). Combining both demographic variables of increased age and increased rates of dementia, it is rational to predict that the number of care aides working in LTRC needed to support our aging population is also only expected to increase with time. As such, there has never been a better time than the present to research the current state of dementia care in LTRC from the perspective of those primarily delivering the care—the care aides.

1.2. Research Problem

Care aides are the backbone of the healthcare team in LTRC. The majority of care aides are employed in LTRC settings and provide the greatest amount of direct care for institutionalized older adults (Kinjerski & Skrypnek, 2008). Care aides thus hold the greatest potential for having the largest impact on residents' quality of life (Kinjerski & Skrypnek, 2008). Quality of life for vulnerable residents, such as those living with dementia in LTRC, is highly dependent on the well-being and continuity of their caregivers (Nolan, 2007). The problem is that literature reviews consistently reveal, compared with other healthcare services, a paucity of research surrounding LTRC services, processes, and outcomes (Caspar, Cooke, Phinney, & Ratner, 2016; Squires et al., 2015). In addition, the research that is conducted in LTRC focuses almost exclusively on the perspectives of licenced healthcare professionals (e.g., Registered Nurses and Licenced Practical Nurses) and ignores the perspectives of unregulated, unlicensed healthcare members, such as care aides (Caspar, Ratner, Phinney, & MacKinnon, 2016; Mallidou, Cummings, Schalm, & Estabrooks, 2013; Scales, Bailey, Middleton, & Schneider, 2017; Squires et al., 2015). The experiences and perceptions of care aides in their role as carers, as well as their relationships within LTRC (with residents, family members, fellow staff members, etc.), directly affect their job performance and thus the quality of care they are able to deliver to residents (Kinjerski & Skrypnek, 2008). Therefore, understanding care aides' experiences and perceptions is essential to our knowledge of best practices within the LTRC culture of care.

The aim of this study is to provide ideas and insights to improve the quality of life of care aides, who represent a significant portion of individuals who work in LTRC settings, and consequently to ensure the quality of care of residents by: (i) gaining a greater understanding of care aides' experiences in LTRC, and (ii) considering the care aides' perceived barriers and facilitators in their care delivery to residents.

1.2.1. Significance and Implications

Coinciding with the booming aging population, the LTRC industry in Canada is currently flourishing and is expected to continue to do so for the coming decades. Unfortunately, there are relatively few publicly subsidized assisted living units in British Columbia, and because of this home care or LTRC is more often utilized for people living with dementia (Cloutier, Penning, Nuernberger, Taylor, & MacDonald, 2017). In 2014, the LTRC industry generated revenues of $10.9 billion and expensed $10.8 billion, of which $7.2 billion were wages and salaries (Government of Canada, 2015). These revenues represent a large proportion of the working Canadian population that is employed in the LTRC sector. Mirroring the size of this workforce is an even larger segment of the Canadian population who are living as residents in LTRC. It has been well documented that residents living in LTRC facilities today are older, more disabled, and closer to the end of life than residents in LTRC a decade ago; however, data on the staff within these settings have not been adequately examined over time (Mcgregor et al., 2010). These numbers show that a large proportion of the Canadian population lives in LTRC while another large proportion finds employment in this sector. This situation, however, is not unique to Canada. Over the past decade, the proportion of populations that receive LTRC services has grown in almost all OECD countries, with a large segment of this growth relating to the oldest old in society (Muir, 2017).

There are two issues at play. First, care aides represent this substantial body of workers in Canada and very little is known about them. What is known is that care aides are routinely injured on the job and report high levels of burnout and turnover (Meyer, Raffle, & Ware, 2014; Rai, 2010). It is also known that, like the residents they care for, care aides are a marginalized population. Due to a global shortage of nurses, there is an increased number of unregulated and unlicensed individuals who are employed in elder care as care aides (McKenna, Hasson, & Keeney, 2004). On the one hand, these unregulated and unlicensed care aides risk making the job of trained care aides more difficult and negatively affecting the quality of care given to residents. On the other hand, these unregulated care aides are themselves at risk with limited job security and unsafe working conditions. Although care aides are invaluable members of the healthcare workforce, literature is limited on the details of their job and their perceptions of their role within LTRC (Ginsburg et al. 2016 Castle, Engberg, Anderson, & Men, 2007). Even compared to residents, care aides are thought to be the least-researched population in LTRC (Wei et al., 2015).

Second, given the increasing age of our population and the concurrent growth in the prevalence of dementia, it is predicted that the care aide workforce is desperately needed to grow and strengthen as well. The value in addressing the issue of care delivery in LTRC from the perspective of the care aides is for gerontological researchers to gain a better understanding of the current state of this occupation and how it may be supported in the future so that we can ensure good dementia care delivery in LTRC settings.

1.3. Purpose and Objectives of the Study

The purpose of this study was to understand the experience of being employed as a care aide in LTRC. The specific objectives associated with the purpose are:

> Objective 1: to examine care aides' experiences leading up to and entering LTRC, especially during education and training;
>
> Objective 2: to examine the relationships of care aides with residents, family members, fellow staff members, management, and the union;
>
> Objective 3: to examine care aides' beliefs regarding their role in LTRC as viewed in the LTRC settings and the greater society;
>
> Objective 4: to examine care aides' perceived barriers and facilitators in their delivery of care to residents

This study aims to increase the quality of care for a large segment of Canada's most seriously ill older adult population who live in LTRC by addressing the gap in gerontological knowledge surrounding the perspectives of care aides. This problem was addressed using a variety of qualitative methods, including (i) semi-structured interviews (70 hours) with 31 care aides; (ii) naturalistic observation (170 hours); and (iii) reflexive journaling (20’000 words). All data was generated from one complex-care floor located within a campus of care facility in rural and remote Western Canada. Thematic analysis was used to examine all data sources. Qualitative methodology was the best way to approach this subject because it allowed for the scientific and in-depth description of the experiences and perceptions of care aides in LTRC. Findings from the study will inform facility administrators, healthcare planners, and nurse educators about the implications for changing care practices as well as implementing educational programs to empower and help facilitate care aides in their delivery of care to residents in LTRC. Findings from this study will also be added to the growing body of knowledge that surrounds care aides in LTRC.

1.4. Thesis Overview

This thesis was written in eight chapters. Chapter 1 provides the background for, explains the significance of, and outlines the purpose and objectives that guide this study. Chapter 2 presents a review of the relevant literature and provides the conceptual context for this study. The chapter is divided into four main sections. The first section presents a review of the importance of LTRC. The second section is a history of dementia care approaches utilized within LTRC. The third section describes the role of care aides in LTRC environments. The fourth section reviews the guiding theoretical approaches for this thesis, mainly institutional theory and critical gerontology theory. Chapter 3 explains the method of inquiry used in this study, namely an ethnographic approach, as well as the method of research. This thesis then transitions to a discussion of the study findings, which are covered in chapters 4, 5, and 6. Chapter 4 begins with an introduction to the study findings and then presents an overview of the location in which the ethnographic research was conducted. The chapter also introduces the reader to the study participants, the care aides, by examining how they came to choose their role and what their experiences were during their education and initial entry to LTRC. Chapter 5 presents findings related to the relationships that care aides have within LTRC. Chapter 6 discusses the challenges that care aides reported having experienced in LTRC and how these present themselves as barriers in their care delivery to residents. Chapter 7 presents a discussion of study findings in relation to the two theoretical concepts guiding this study, power and institutionalization in LTRC. Chapter 8, the final chapter, presents the summary, recommendations and conclusions.

1.4.1. Positioning Statement

These research questions reflect my own long-time association with and interest in dementia care in the following three ways: (i) I identify myself as a dementia care advocate and believe that care aides are currently and will continue to be the backbone of care delivery in LTRC for individuals living with late-stage dementia; (ii) my biological mother worked as a care aide in LTRC when I was in my adolescence, and I spent a great deal of time from an early age in the LTRC environment and was exposed to some of the struggles that care aides experience within this occupation; and (iii) most of the care aides as well as residents in LTRC are women and, as a feminist, I am determined and motivated to make this role better both for the residents and those who care for them. For further information on my process through this thesis, please review my reflexive analysis, which can be found in the final chapter (Chapter 8: Discussion and Conclusion).

Chapter 2. Literature Review and Conceptual Context

This chapter highlights the increasing importance of long-term residential care (LTRC) for our aging population, particularly for people living with dementia. The chapter begins with a discussion of the current state of care in LTRC in Canada, including a review of dementia care approaches applied within this setting and an overview of the culture change movement within LTRC. The chapter then examines the current discourse surrounding the role of care aides in LTRC, including their: (i) education; (ii) scope of practice; (iii) position within the hierarchy of healthcare; (iv) role as dementia carers; (v) response to staffing issues (retention, turnover, and burnout); and (vi) involvement in research. The chapter concludes with a discussion of the theoretical guiding approaches for the research as well as the purpose and significance of the study.

2.1. Long-Term Residential Care and Dementia

As previously mentioned, most people living with dementia and their care partners would rather age in place at home, and LTRC is generally considered a "last resort" (Banerjee, 2007). There are several reasons why LTRC is seen in this negative light, including concerns that (i) the person's cognitive function will decline further and more than what one would expect to see if the person stayed in his or her home in the community; (ii) unnecessary and harmful physical or chemical restraints will be used on the person; and (iii) the person with dementia will experience a severe lack of social engagement in these settings (Freeman, Spirgiene, Martin-Khan, & Hirdes, 2017). There is also a fear of abuse and neglect toward the person with dementia in these settings, either by other residents or staff members (Stevens, Biggs, Dixon, Tinker, & Manthorpe, 2013). Stories in the media sensationalize this often most-feared reality of institutional care. Examples include popular press articles such as "man, 91, dies after being left unchecked in B.C. care home for several days" (The Canadian Press, 2012), or the recent exposé declaring that the "mistreatment and abuse of patients in long-term care homes is anything but rare" (Morris, 2017). The stories that the media chooses to highlight leave little to the imagination regarding the worst possible situations waiting for care partners or their loved ones in LTRC. The recent horrific story from Woodstock, Ontario, of the “Angel of Death,” who has been charged with the murder of eight LTRC residents (Tu, 2017), only furthers the fears of residents and family members. Individuals with dementia and their care partners also have reported concerns regarding aggression, violence, and even murder at the hands of other residents (Lachs et al., 2016). Recent cases such as the “Toronto senior sentenced to life in prison in killing of long-term care home resident” only add to these concerns regarding the safety and well-being of residents in LTRC (Miller, 2017). With stories such as these circulating in the media, it is no wonder that LTRC is often seen as the absolute last resort for many individuals.

These fears may be exacerbated for family members when their loved one in LTRC has special needs that require the person to have more care or more specialized care in relation to other residents. For people living with dementia, family care partners may understand the exact nuances of their loved one’s care regime and, in most cases, knew the person prior to the onset of cognitive impairment and have a shared history. The care partner may be concerned that when the person with dementia expresses “difficult behaviours” in LTRC that staff and fellow residents may be unprepared to respond in a safe and respectful manner (Buhr & White, 2006). Family care partners also fear that their loved one may experience aggression or upsetting behaviours from a fellow resident who is also living with dementia. Underlying all of these fears is that the quality of life of the individual with dementia will rapidly deteriorate once he or she enters LTRC (Beerens et al., 2015). When people in Canada enter LTRC, evidence shows that they are more likely to stay until death, although single or multiple hospitalizations can be common in their overall service trajectories (Neiterman, Wodchis, & Bourgeault, 2015). In this sense, LTRC may literally be the last resort for people living with dementia and their care partners because the person is no longer able to maintain safety and well-being at home.

Although clearly not the ideal situation for many individuals with dementia and their families, there are several well-documented reasons why it may be preferable for people with severe needs, such as those seen during the advanced stages of dementia, to utilize the services of institutional care such as LTRC. Cloutier et al. (2017) examined the common service use trajectories and predictors among a cohort of people with dementia who received publicly funded LTRC in Canada. For some people, it might be a decision about the safety or quality of life of the person living with dementia or the care partner, or it can be due to a need to reduce health system costs. For example, people living at home can be at greater risk of hospitalization, particularly if they have dementia (U.S. Department of Health and Human Services, 2014). Individuals living with dementia often experience more challenges and difficulties as they navigate or transition across healthcare systems, and as a consequence they have a greater potential for adverse outcomes and increased hospitalizations due to discontinuities in care, poor compliance, and medication errors in comparison to persons living without dementia (Callahan et al., 2015). Therefore, preventing unnecessary hospitalizations and ensuring safe and appropriate care for people living with dementia is important in terms of reducing overall health system costs, and often entry into LTRC is the most viable solution to this issue (Sivanthan, Lavergne, & McGrail, 2015). Because of these factors, a large proportion of the population of residents in LTRC are people living with dementia.

The current number of residents living in LTRC in Canada that has a diagnosis of dementia is a point of ambiguity and disagreement in the literature. Some researchers report the number to be 45% (Wong et al., 2016), while others estimate upwards of 61% of residents in LTRC who are living with a dementia diagnosis (OSA, 2016). These estimates, however, may not be an accurate representation of the true picture of dementia in LTRC, because many residents living with dementia will not have received a formal diagnosis, which is often delayed or prevented due to the mistaken belief that dementia is a natural consequence of ageing or because of an individual’s reluctance to seek help about his or her memory problems (Frankish & Horton, 2017). There is also a great deal of stigma associated with a dementia diagnosis that has been shown to prevent individuals from seeing a health professional about their symptoms as well as physicians from diagnosing dementia (Herrmann et al., 2017). In fact, in high-income countries, such as Canada, only around half of those affected by dementia actually receive a diagnosis, and unfortunately in low-income countries less than 10%–20% receive a diagnose (ADI, 2015). Because of this, it can be assumed that the current information we have regarding the prevalence of dementia in LTRC is not an accurate representation of the true state of dementia care needs in these settings. What is known is that there is agreement in the literature that nearly more than half of the population in these settings is living with dementia. Therefore, LTRC may be thought of as predominantly dementia care and, as previously discussed, with the aging population and predicted increase in the prevalence of dementia, LTRC will hold even greater importance regarding the state of dementia care in Canada and other nations worldwide. The following section will discuss the approaches that are predominantly used by staff in LTRC settings to deliver care to residents who have dementia.

2.2. Dementia Care Approaches in Long-Term Residential Care

Just as one cannot tease apart the issues of serious mental illness and homelessness (Poremski, Whitley, & Latimer, 2014; Schutt & Goldfinger, 2011;), discussions pertaining to LTRC must also include the topic of dementia. In today’s LTRC environments, dementia is constantly present. Being a resident in LTRC and having dementia is not a mutually inclusive situation; however, due to the prevalence of dementia in LTRC, it is a mutually inclusive circumstance that dementia affects the quality of life of every resident within these settings. The extent of dementia found in LTRC highlights the sheer importance of continuing to include the issues related to dementia within all LTRC conversations and proposed solutions to enhance the quality of life for residents as well as staff.

It is critical to our understanding of dementia care to recognize the historical contribution that different approaches have lent to our current knowledge and practice. This section will cover two main topics: (i) approaches to dementia care and (ii) how these models of care influence LTRC and are influenced in the LTRC setting. The discussion pertaining to paradigms of clinical and social care of individuals with dementia begins with the traditional biomedical model, followed by person-centred care (PCC), and finally approaches to dementia care that have been developed to fill in the gaps of PCC, including relational care, relationship-centred care (RCC), and citizenship. This section will then review the current understanding of dementia care and its influence and implementation in LTRC in relation to care aides, resident interactions, and the culture change movement in LTRC. The purpose of this review is to present the gerontological literature that pertains to care aides and dementia care in LTRC while also building a case for examining the reported experiences and perceptions of care aides who are the predominant care partners for residents in LTRC.

As previously mentioned, a significant proportion of older adults receiving care in LTRC settings are living with dementia. Nearly two decades ago it was estimated that between half and two-thirds of residents in LTRC had some form of dementia (Magaziner et al., 2000; Matthews & Dening, 2002). At present, the rates of dementia and specialized care needs in LTRC have already radically increased over the past two decades, and researchers predict that these rates will continue to steadily rise as the population ages (Swartz et al., 2012). The established fact that most residents living in these settings have dementia has strong implications for the type of care that these institutions provide. How the population of individuals with dementia has traditionally been cared for in LTRC, as well as the current strategies and perceived best practices in dementia care, will ultimately shape the future of how dementia care is viewed and implemented in LTRC.

2.2.1. Biomedical Approaches to Care

The traditional paradigm of clinical and social care of individuals living with dementia is characterised by the management of what have been deemed “challenging behaviours” through various methods, including physical and chemical restraints, pharmacology, and other forms of control and manipulation (Dupuis, Wiersma, & Loiselle, 2012). In North America, unfortunately, the predominate discourse surrounding dementia continues to be framed and understood within biomedical/pathophysiological and psychological/psychosocial models of illness and disease (Caspar, Ratner, et al., 2016; Clarke, 1999). Even though both practitioners and researchers are aware of the dangers and limitations of continuing to espouse the biomedical model in LTRC, recent ethnographic studies in LTRC have found that very limited changes in discourse have yet to be adopted in actual practice (Caspar, 2014; Kelson, 2013), and the theoretical foundations of the biomedical perspective unfortunately still remain true in dementia care (Innes et al., 2012). These models of care neglect the person’s vital need for social relationships and interactions and his or her need to be treated as an individual, as well as undermines the individual’s personhood (Kitwood & Bredin, 1992). It has been well documented that delivering care services in a rigid, time-managed, and task-oriented manner can cause care providers to struggle to be flexible and responsive to the changing needs of people with dementia, as well as to fail to deliver the appropriate care when it is needed (Nolan, 2006). While there are benefits to the biomedical model for some diseases, the main disadvantages are that this model does not take into account the perspective of the individual with dementia (Bartlett & O'Connor, 2010), and traditionally views the person with dementia as passive and dependent (Baars, 2006; Kontos, 1998). Also, although those providing dementia care may have altered their practices over time, it is now widely recognized that there are many different types of dementia and that dementia symptomatology itself varies greatly, with Alzheimer's disease alone suspected of including at least three distinct subtypes (Bredesen, 2015). Because of the disadvantages of the biomedical model and the varying symptomatology of dementia, the emphasis on personalized care for someone living with dementia that matches his or her specific symptoms and needs is increasingly more important. Care in LTRC that has predominantly been set within a provider-driven, medical model is shifting toward a more person-centred, social model (Brooker, 2003; Chappell, Reid, & Gish, 2007; Rahman & Schnelle, 2008). This paradigm shift in understanding dementia and dementia care is discussed in the section the follows.

2.2.2. Person-Centred Care

Since the late 1980s, the literature reveals that researchers, advocates, and clinicians have increasingly sought alternatives to the traditional biomedical care models, most often in the form of person-centred care (PCC; Kelson, 2013). Thomas Kitwood (1937–1998), a pioneer in the field of dementia care, forced the discussion of who or what a “person” is in the context of dementia care. In his book, *Dementia Reconsidered: The Person Comes First* (1997), Kitwood discusses a philosophical approach to formal caregiving that uses a person's unique personal needs to guide care practices, thus enabling the individualization of care plans and care routines. Kitwood (1997) challenged assumptions about the personhood of people living with dementia by viewing personhood as a status (or standing) that could be bestowed upon one human being by others in the context of social relationships. The cornerstone of this idea is that social relationships are based on recognition, respect, and trust and that all human beings have value as “persons” regardless of their cognitive abilities. Kitwood (1997) used the term *person-*

centred care to bring together ideas and ways of working that emphasize communication and relationships that involve the individual living with dementia. PCC recognizes the uniqueness and intrinsic value of the individual who is living with dementia (Kitwood, 1997).

The person-centred approach originated from the work of Carl Rogers, a psychotherapist who developed the “client-centered approach” to psychotherapy in the 1950s (Kirschenbaum, 2004). Rogers argued that clients do not need the judgment, advice, or direction of experts; instead, they need “supportive counsellors and therapists to help them rediscover and trust their own inner experience, achieve their own insights, and set their own direction” (Kirschenbaum, 2004, p. 120). Kitwood (1997) elaborates on this by describing a state of “ill-being” that traditional care often produces in the person with dementia whereby the diagnoses and medicalization of individuals with dementia often place them within a system that undermines their personhood. Kitwood not only provided a model of dementia that highlights the interaction between neurological impairment, the psychology of the person with dementia, and the social environment, but also strongly advocated for the respect of the personhood of the person with dementia. He emphasized that individuals living with dementia are not merely biological entities or the “carriers of dementia”; they are at risk of losing their personhood.

Personhood

Personhood is the underlying theory that supports PCC (Kitwood, 1997). Being human has been equated with being a person in the sense that being in and of itself is the sole criteria. Kitwood (1997) claimed that personhood is sacred and unique and that every person has an ethical status and should be treated with deep respect. Traditionally, personhood has focused mainly on cognitive abilities, such as consciousness, rationality, intentionality, memory, reciprocity and the capacity to communicate (Harrison, 1993). More recently, this focus on cognitive abilities has been challenged as the de facto way of understanding personhood. As a result, understanding personhood can be divided into two schools of thought: (i) that personhood relates to an individual’s possession of specific cognitive capabilities; or (ii) that personhood is socially based and relates to a human being’s position within a morale community that advocates for the social inclusion of everyone, irrespective of cognitive abilities (Baldwin et al., 2007). Regarding the first school of thought, which is the more dominant view of personhood and is based on one's ability to reason, the premise is that when one loses the ability to reason, the person loses his or her sense of self. Therefore, it is assumed that to be a person, you must be capable of rational thinking and memory. Since the defining feature of dementia is a progressive decline in cognitive function, the disease has historically been understood to strip the diagnosed person of his or her personhood status, leading to a "loss of self" (Kitwood, 1997). An assumed "loss of self" has been noted in the literature as the most horrifying experience of dementia (Kelson, 2013). Kitwood contributed to our understanding of dementia by emphasizing that a relationship with the person based on recognition, respect, and trust should be preserved at all costs, even as the person receives a diagnosis of and progresses through dementia.

Regarding the second school of thought, the social nature of personhood, Kitwood defines personhood as a "status or standing bestowed upon one human, by others, in the context of social relationship and social being" (1997, p. 8). Persons with dementia exist in a network of relationships that are created and maintained through interactions with others. Considering this, Kitwood argued that these changes were not just the result of changes in the brain, but also consequences of a complex interaction between neuropathology and the person's psychosocial environment (1997). Therefore, with this understanding, many of the difficulties individuals living with dementia experience are not merely consequences of the disease but are also brought about by negative interactions with others (Kitwood, 1997). From this rationalization Kitwood (1997) coined the term *malignant social psychology,* popular examples of which include infantilization, disempowerment, or objectification. For Kitwood, expressions of malignant social psychology are often seen as the symptomatology of gaps in communication between those living with dementia and those who are delivering direct care to them.

The importance of the relationship between care partners and the person living with dementia was discussed in detail by Kitwood. He emphasized the relational nature of PCC and the need to value carers. Further, he stated that carers cannot deliver PCC unless their own emotional strains are recognized, they experience feelings of being respected and valued, and they have the necessary communication skills. Brooker (2007) has suggested the acronym VIPS to encapsulate the broader meaning of PCC: People with dementia and their carers must be ***V***alued and treated as ***I***ndividuals; the ***P***erspective of the person with dementia must inform our understanding; and the person's ***S***ocial environment must be attended to because of the fundamental importance of relationships in sustaining personhood. Although Kitwood's (1997) emphasis was primarily based on the psychological domain of care, the promotion of personhood as the principal aim of his conception of PCC extended to interpersonal, social aspects of care (Kelson, 2013; Baldwin & Capstick, 2007b). Kitwood (2007) stressed the influence of interpersonal relations as an essential aspect to understanding the dementia experience, theorizing that at least some of the deterioration is not caused by the disease itself but rather by how the individual has been treated, which then results in a perceived loss of personhood (Kitwood & Bredin, 1992). Sabat (2002) also argued for the importance of recognizing the self in people with dementia.

A focus on personhood in dementia can be credited with developing dementia care practices in three critical ways: by (i) promoting a more holistic and hopeful understanding of dementia; (ii) offering an important strategy for beginning to individualize the experience of dementia; and (iii) changing the language we use around dementia and emphasizing the importance of communicating with people who have dementia (Bartlett & O'Connor, 2010). Thus, the use and understanding of personhood have successfully and openly brought the person with dementia into the discussion. The "dementia narrative" is gaining momentum as a pinnacle force for understanding the dementia experience through the eyes of someone living with the disease. It is well documented that the perspectives of the family care partners of people living with dementia are included in the literature (McCabe et al., 2016); however, the experiences of those living with dementia have only recently begun to be included. For example, Borley, Sixsmith, and Church (2016), offer an important in-depth analysis of the changing self in women who are living with dementia. As previously stated, most individuals with dementia are women (ADI, 2015). Thus, it is important to understand the lived experiences of women with dementia who are being cared for. By understanding the meaning of being cared for, all of the other persons involved in the dementia discourse—clinicians, researchers, care partners, advocates—are able to better understand the lived experience of those being cared for and thus can help to facilitate more effective care delivery (Borley, Sixsmith, & Church, 2016).

A PCC environment emphasizes the individuality of the person with dementia, the development of consistent and caring relationships, malleable care routines that are respectful of residents' values and preferences, the need to foster a rich social environment (Brooker, 2007; Nolan et al., 2004). Advocates of the new culture of care (Kitwood, 1997; Ronch, 2004) associated with PCC emphasize a departure from task-based, custodial care that prioritizes "bed-and-body work" (Gubrium, 1997). Proponents of personalized modes of caring oppose notions of hopelessness and despair with the proposition that given positive relationships and a supportive social milieu, persons with dementia can achieve relative levels of positive well-being (Kitwood, 1997). PCC shifts treatment emphasis from pathologizing behaviour to understanding the meaningfulness of actions (Dupuis et al., 2012). Unfortunately, traditional care that tends to focus on rationality serves to undermine personhood by ignoring the fundamental need for social relationships and interactions as well as a desire to be treated as a complex and unique individual (Kitwood, 1997).

As previously noted, Kitwood (1997) used the term *person-centred care* to bring together ideas and ways of working that emphasize communication and relationships that involve the individual with dementia. PCC is both a value-based philosophical approach as well as a practice-based framework (Brooker, 2007). Although Kitwood's PCC primarily focuses on persons with dementia, it is important to note that PCC also acknowledges the personhood of other older and frail residents who are living with or without dementia, as well as the care aides who directly interact and care for them in LTRC. In an organization that delivers a human service, there will be a close parallel between the way employees are treated by their superiors and the way clients themselves are treated (Kitwood, 2007). If the employees are abandoned and abused by their superiors, the risk is that clients will be abandoned and abused too. Alternatively, if employees are supported and encouraged by their superiors, they will take their own positive sense of well-being into their day-to-day work. If an organization is committed to providing excellent care to its residents living with dementia—by recognizing their personhood—it must also be committed to acknowledging the personhood of all staff members who support people with dementia, especially those in direct contact with them—the care aides (Kitwood, 1997). If we understand how an organization treats its care aides, it may give insight into how the care aides perceive their own roles as carers as well as how they perceive the residents they care for.

In many LTRC facilities, PCC has been thought to have become synonymous with best practices in dementia care (Brooker, 2003). It is important to recognize that those who deliver personal care in LTRC (which is predominantly the role of care aides) do not necessarily provide care in a way that purposely negates personhood. Often the culture of care established in certain LTRC settings may have embedded beliefs, values, policies, structural issues, or behavior patterns that may unknowingly be propagating poor practices because of the innate systemic, institutionalized disregard for the personhood of residents and care partners. Based on a review of PCC literature conducted by Caspar (2014), there are three components of PCC that are essential to the relationship between care aides and the residents that they care for:

1. Care providers must know and value the needs, concerns, and preferences of their care recipients.
2. Care providers must be able (based on their skills, abilities, and experiences) and enabled (based on their access to information, resources, and support) to adjust their care practices to meet the care recipients' needs, address their concerns, and honour their preferences as consistently as possible.
3. A reciprocal relationship between care partners and care recipients (based on mutual trust and respect) must be formed, acknowledged, and supported. The social nature of the relationship between care partner and care receiver must be established. This speaks to the importance of the social nature of the role of care aiding.

The use of person-centred terminology is frequent in both the literature and in practice and has come to denote quality care; however, it's significance in practice can be critiqued. While attention to personhood and PCC in the delivery of care in LTRC institutions has achieved much in terms of raising consciousness about the intrinsic value of individuals with dementia and offering the potential for future constructive changes in the culture of care, the concepts of personhood and PCC are not without limitations, which the following section will review.

Critique of Personhood and Person-Centred Care

Within the context of dementia care, Kitwood's work has been the most influential in challenging pathophysiological and biomedical approaches by offering an alternative paradigm for understanding dementia (Dupuis et al., 2012). Until recently, the majority of Kitwood’s ideas on personhood have been either uncritically accepted or rejected as having limited significance for actual practice (Dewing, 2008). There is also concern that efforts to support social practices that affirm personhood are in danger in the context of an increasingly risk-averse culture that is led by a growing bureaucracy within healthcare settings (Parker, 2001). Although PCC has arguably been the most important development in dementia care approaches since the early 1990s (Bartlett & O’Connor, 2010), it has not been without criticisms. As with PCC, reaching theoretical consensus on personhood to facilitate implementation in practice is an ongoing challenge (Kelson, 2013). While personhood is essentially an apolitical concept concerned with psychosocial issues, it is too limiting for our understanding of dementia care (Bartlett & O’Connor, 2007).

On a foundational level, PCC is somewhat ambiguous and therefore often poorly operationalized and may mean many different things to different people (Kelson, 2013). Because of this, a consensus has yet to be achieved on the exact meaning of the concept of PCC (Edvardsson, Winblad, & Sandman, 2008; Passalacqua & Harwood, 2012). The complexity of PCC indicates that there is still a lack of conceptual clarity to its meaning (Barbosa, Sousa, Nolan, & Figueiredo, 2015). One of the main issues of PCC is that historically it tends to focus mainly on the person with dementia and to neglect the experiences of the formal care partners (Nolan, 2007). Other criticisms are that PCC is too idealistic and thus unworkable on a day-to-day basis and that it conflicts with the practice and systemic process realities of LTRC as well as with established models of service delivery (Nolan, 2007). Because LTRC facilities have predominantly not addressed pre-existing organizational and staffing problems, the practical implementation of PCC throughout a facility is just not feasible (Caspar, O’Rourke, & Gutman, 2009). Barbosa and colleagues (2015) conducted a systematic review to assess the impact of PCC approaches on the job satisfaction, burnout, and stress of staff who deliver direct care to residents in LTRC settings. Due to limitations in methodological weaknesses and the heterogeneity of the studies, it was not possible to draw firm conclusions about the efficacy of PCC approaches for direct care staff. They were able, however, to highlight a tendency toward the effectiveness of PCC approaches in LTRC.

Another critique of PCC is the notion that the person living with later stage dementia does not have agency over his or her own self, which is a contentious issue (Bartlett & O'Connor, 2010). Agency is broadly defined as the capacity of an individual to influence the circumstances in which he or she lives. This relates to the proposition that the person with dementia is an active agent who continues to engage in the preservation of his or her selfhood. Bartlett & O'Connor (2010) bring to light the way in which Kitwood (1997) speaks about how certain care practices undermine personhood without any reference to the agency of people with dementia. The implicit assumption is that individuals with dementia are necessarily passive in the face of external forces and that it is the caregivers' task to ensure personhood in people with dementia.

Along the same lines as lack of agency over oneself, another noted problem associated with a PCC approach is the underlying focus on the maintenance of an individual with dementia's current cognitive status and not on the person's growth, development, and maturation (Bartlett & O'Connor, 2007). There is a tendency to conceptualize PCC in a way that may inadvertently align with the previously established biomedical model, in that PCC may effectively be discounting growth and maturation in people with dementia by relegating personal transformation to neuropathological changes associated with the disease rather than with an individual's experienced life course (Bartlett & O'Connor, 2007). Like any other person, individuals living with dementia may change their minds and their preferences, they may want to experiment, and they may legitimately lose interest in things that once interested them. It has been argued that the PCC approach does not leave room for older adults in LTRC with dementia to change, grow, and develop. Nor does it allow for individuals with dementia to have agency over their own personhood. Nolan (2004) has suggested that PCC not only fails to improve institutional care, but also perpetuates poor standards of care by failing to consider the impact of both the interpersonal processes and intrapersonal experiences of giving and receiving care. Dupuis et al. (2012a) takes this criticism one step further in claiming that PCC is shrouded in good intentions but that paternalistic approaches often place "patients" or "clients" at the centre of care decisions and rarely, if ever, actively involve them in the actual decision-making process (Dupuis et al., 2012a).

Critics express concern that PCC focuses too heavily on residents' autonomy and decision-making capacities (Nolan, Davies, Brown, Keady, & Nolan, 2004) while overlooking the interdependencies central to care relationships over the life course (Lloyd, 2004; Rockwell, 2012). Nolan et al. (2002) discussed that a pitfall of PCC may be that it fails to "fully capture the interdependencies and reciprocities that underpin caring relationships" (p. 203). This criticism led to the emergence of relationship-centred models of dementia care. The focus on relationships led to what has been described as the forth paradigm of understanding care for people with dementia in LTRC (Bartlett & O'Connor, 2010).

2.2.3. Relationships

Just as our understanding of dementia care has changed over time, how dementia itself has been conceptualized has also evolved drastically. Relationship-focused care encompasses a more dynamic, contextualized perspective of care than PCC. This vision of care is based on two critical themes discussed by Bartlett and O'Connor (2007). First, people with dementia are influenced and they influence. This first theme in relationship-focused care emphasizes the importance of having a bi-directional, interactive understanding of the agency of older adults with dementia in LTRC. The second theme emphasizes the importance of interpersonal and social relationships as well as the significance of a more textured, multidimensional lens for conceptualizing the experience of the individual with dementia. Relationship-focused care, as discussed by Bartlett and O'Connor (2007, 2010), works to highlight the importance of attending to the relationships between and among family members, people with dementia, and formal care partners as an essential element of quality dementia care. This model focuses on interconnectedness and partnership. Relationship-focused care is an important extension beyond PCC because it captures the expectations of the person with dementia while retaining status as an active partner throughout the dementia trajectory (O'Connor et al., 2007). There are two types of relationship-focused care that are discussed further in this section, beginning with relationship-centred care and moving to the more recent relational care.

Relationship-Centred Care

The practical issues of PCC in LTRC have long been discussed regarding dementia care. As previously mentioned, LTRC often espouses a PCC philosophy, yet it operates according to a medical model with highly structured regulatory and administrative requirements. Because of this, there is often tension between the priorities of the resident and those of the care organization. A relationship-centred approach (RCC) is one solution that has been proposed and has gained traction. This approach to dementia care was developed to balance out the focus on the person with dementia to include those who formally and informally deliver care (Ryan, Nolan, Reid, & Enderby, 2008). In other words, RCC highlights the nature of dementia care triads that comprise the person with dementia, his or her informal carer, and the health and social professional (Adams & Gardiner, 2005). RCC attempts to address the limitations of PCC by contextualizing the individual living with dementia within his or her relationships with others (Nolan, Ryan, Enderby, & Reid, 2002). RCC focuses on the personhood and interconnectedness of residents, their families, and care staff. Nolan and his colleagues (2004) suggested that the conceptual shortcomings of PCC are rooted in their inability to fully account for the reciprocities and interdependencies that reinforce all caring relationships.

RCC is based on the Senses Framework (Nolan et al., 2004; Ryan et al., 2008), which is guided by the belief that an “enriched environment” is necessary for all parties involved in care. This enriched environment should include relationships that promote a sense of security, belonging, continuity, purpose, achievement, and significance. The impetus of RCC is to “fully capture the interdependencies and reciprocities that underpin caring relationships” (Nolan et al., 2002, p. 203), and emphasizes the importance of relationships to quality care. RCC makes two important contributions to the understanding of dementia care: (i) the expectation that the person living with dementia will retain status as an active participant and partner in the dementia care experience (Bartlett et al., 2010); and (ii) the conceptual shift from the autonomy and individuality that underpins person centeredness to interdependence and rationality (Dupuis et al., 2012).

Nolan et al. (2004) advocated that relationships are critical, but that there is a need to account for not only the relationships between residents and their families, but also the relationships between care staff and other professionals that exist within the LTRC network. Although RCC has been developed to fill in the gaps of PCC, it too is not without criticism. One of the concerns with RCC is that is difficult to pinpoint the conditions that produce and maintain positive relationships in care. This continues to be an obstacle for the implementation of RCC (Nolan, 2004). The most notable shortcoming of RCC is that there is no discussion of other influencing factors beyond the home or facility itself. Relational care (RC) is one solution that has been proposed to fill in the gaps of RCC (Rockwell, 2012), and is discussed in the section that follows.

Relational Care

While early research and literature focused on personhood and PCC, more recent research recognizes the importance of relationships, specifically, the understanding that quality care must occur in the context of a relationship (Brooker, 2007). A relational approach recognizes that the actions and behavior of individuals who are living with dementia are not determined solely by an underlying neuropathology, but also by their relations, personal histories, and interactions with others as well as by how they are perceived within social contexts (Bartlett & O’Connor, 2010).

Nedelsky (2012) described individuals as “in basic ways constituted by networks of relationships of which they are a part—networks that range from intimate relations with parents, friends, or lovers to relations between student and teacher, welfare recipient and caseworker, citizen and state, to being participants in a global economy, migrants in a world of gross economic inequality, inhabitants of a world shaped by global warming” (p. 19). It is these relational patterns that shape who an individual is (Nedelsky, 2012).

Rockwell (2012) focused on the conceptualization of care delivery and the movement from PCC to relational care. She argued that the literature on relational care and relational autonomy supports an expanded focus on the resident within a circle of family, caregivers, and community. Also, the language of PCC is semantically linked to autonomy and independence in that it positions the resident as an isolated unit of consideration and focuses on his or her right to make decisions. Rockwell asserted that this school of thought lends itself to a conceptualization of care as moving unidirectionally toward the resident, without return benefit to the carer (Rockwell, 2012).

Along similar lines, Lloyd (2004) presented two reasons why the current emphasis on values such as autonomy and independence in care inhibits the delivery of quality care as people age. First, the language promotes an idealistic image of aging that dissociates older adults who may have dementia or other health concerns and who are dependent. Second, highlighting liberal notions of independence disregards the reality and necessity of interdependence at all ages of life. Lloyd concluded that "*the needs of older people at the end of life should be considered, not only in relation to their individual rights and claims but also in relation to their connectedness with others and the ethics of practices concerned with their care and well-being*" (p. 247).

Rockwell (2012) stated that shifting attention from strictly person-centred to more relationship-focused care offers creative ways to improve the socio-emotional milieu of residential facilities even though they are restricted by higher-level policies or funding priorities. She stressed the importance of recognizing the social ties that residents, staff, and the LTRC facility have to the wider community, rather than focusing on the facilities as self-contained environments. Many residents have pre-existing social supports outside of the LTRC facility (religious ties, friends, families) that may all be a source of meaning and comfort in ways that the resident may personally prefer (Rockwell, 2012). Rockwell described how events, projects, and interactions with ties outside the facility can also challenge ageist myths and collapse the physical and social space between the residents and their wider community. Practices that support RC may include providing opportunities for social interaction as well as creating opportunities to speak with residents about their values, feelings, and concerns while also crucially considering their family and friends in discussions of care (Banerjee & Rewegan, 2016).

Recent research involving RC in LTRC shows that workers and families highly value relational care and that it may form the basis for meaningful family participation (Barken & Lowndes, 2017). RC may facilitate the mitigation of organizational barriers that are seen in LTRC (Rockwell, 2012); RC is not, however, a perfect model. One of the criticisms of RC is that, like PCC, the structural and systemic issues present in LTRC may prevent staff from having the time, or finding the time, to foster relationships with residents as a valuable use of their work hours (Barken & Lowndes, 2017).

Society’s progression of understanding about dementia has taken significant turns over time. The literature on dementia care recognizes the importance of citizenship as the fourth and most recent movement (Bartlett & O’Connor, 2010). A citizenship perspective addresses some of the inherent gaps that are found in both person-centred and relationship-focused approaches (Bartlett & O’Connor, 2007).

2.2.4. Citizenship

Initially, dementia was accepted predominantly as a natural sign of aging (i.e., senility). The second shift was understanding dementia as primarily a biomedical condition. The third shift was a more relational understanding of dementia that addressed the importance of seeing the person beyond merely the medical situation at hand. Now, the most recent shift in the dementia paradigm, citizenship, involves taking into consideration the importance of surrounding responses and relationships within broader discourses and sociopolitical practices (Bartlett et al., 2010). Citizenship has deeper implications than personhood because it moves into the realm of political discourse, particularly the idea that participation or inclusion in society is inevitably shaped by power dynamics (Bartlett & O’Connor, 2007). Citizenship extends relationship-focused approaches by including an individual’s relations with others into the broader social-political landscape and thus addresses influences regarding individual experiences with and access to healthcare and social institutions (Bartlett et al., 2010).

The concept of citizenship highlights questions of social justice by bringing to the foreground the influences of socially ascribed categories on the experiences of persons with dementia (Bartlett & O’Connor, 2007). This framework calls for residents in LTRC, including those with dementia, to be considered citizens who should enjoy access to the same rights as other members of society. Citizenship helps to contextualize the care of individuals with dementia in LTRC within a broader socio-cultural and political lens (Kelson, 2013). In this sense, citizenship implies that participation or inclusion in society is inevitably shaped by power dynamics (Bartlett & O’Connor, 2007). By broadening the conceptual lens to include citizenship in sociological ideas about agency, structure, and anti-discriminatory practice, the field of dementia care can move forward (Bartlett & O’Connor, 2010). In this fourth shift in dementia studies, one where sociopolitical context becomes more visible, social citizenship emerges as a pivotal concept for expanding thinking and practice (Bartlett & O’Connor, 2010). Alongside the citizenship of those with dementia is the citizenship of the formal and informal dementia care partners. Alongside the developments in dementia care paradigms utilized within LTRC settings has been a growing initiative to change the entire culture of LTRC. The section that followings reviews the culture change movement within LTRC.

2.2.5. Culture Change in Long-Term Residential Care

Over the past few decades many, although clearly not all, LTRC settings have undergone a transformation in philosophy and organization that is often referred to as “culture change”—a movement that encompasses progressive models of care such RCC and RC and with a heavy focus on PCC (Bangerter, Heid, Abbott, & Van Haitsma, 2016; Barken & Lowndes, 2017). In general, culture change is a broad and diffuse movement characterized by shifts from care settings based on a hospital-like model that aims to provide safe, standardized clinical care to a home-like model that prioritizes residents’ autonomy and quality of life (Koren, 2010; White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). Currently and historically, LTRC facilities are known and criticized for being under resourced institutions where older, frail adults are segregated from the rest of society to spend their final years enduring routine, medicalized care (Johnson, Rolph, & Smith, 2010); focusing on residents’ medical needs and employing profit-making measures; and overlooking social care and other essential variables that contribute to resident quality of life (Armstrong & Canadian Centre for Policy Alternatives, 2009). As a counter to criticism, culture change is complex and dynamic and has been described as follows:

> In general, culture change is a process, and as such, the term connotes a transformation of [LTRC] that goes beyond superficial changes to an inevitable re-examination of attitudes and behavior and a slow and comprehensive set of fundamental reforms. (Rahman & Schnelle, 2008, p. 143)

Although culture change often espouses the development of close and collaborative relationships between residents, their family members and friends, workers, and the broader community (Koren, 2010), it has been noted that the concepts RCC and RC are less popular then PCC, yet they both have gained popularity within the culture change movement (Edvardsson et al., 2008). Culture change can vary in scope and scale and can take on many different forms in LTRC. Changes include aspects such as cross-training workers, organizing residential areas into small "households," creating environments that appear more home-like, enhancing the dining experience, soliciting resident opinions on daily routines, crafting resident biographies for care aides, and writing up care plans in the residents' voice. Interestingly, Gibson & Barsade (2003) found that cultural norms are more effective in influencing behavior than are formal control systems (e.g., written policies and procedures or supervisory monitoring). Thus, culture change encompasses system-wide changes in practice that occur as a result of both intrinsic and extrinsic motivation (Gibson & Barsade, 2003). Grassroots organizations such as the Pioneer Network (a national group based in the United States that originally formed as an umbrella organization for the culture change movement) were created with the goal of facilitating the delivery of PCC in LTRC.

The Eden Alternative is the most well-known organization associated with the culture change movement and is dedicated to creating quality of life for elders and their care partners by transforming the communities where they live and work through person-centred principles and practices (http://www.edenalt.org/). Co-created in the United States in the early 1990s by Dr. Bill Thomas and Jude Thomas, The Eden Alternative advocates that elders interact with children, pets, and plants to help eliminate the feelings of boredom, loneliness, and helplessness that are at the core of the suffering elders experience in LTRC (Thomas, 2003). Ten principles guide The Eden Alternative's mission to improve the well-being of elders, including that daily life activities should be imbued with variety and spontaneity and that meaningful activity is essential to human health. Relationships are what humans find fulfilling, not meaningless scheduled activities that systemically suppress the spontaneity of a rewarding life—the same is true for institutionalized older adults. The real impact of the Eden Alternative is a culture of change that, instead of promoting medication and treatment as the axis of LTRC, promotes a life that revolves around close and continuing contact with people of all ages and abilities, as well as plants and animals, as the foundational culture within LTRC settings. The Eden Alternative is equally concerned with the needs and quality of life of direct care staff as also affecting the culture of care in LTRC (Thomas, 2003).

2.3. Care Aides in Long-Term Residential Care

This section gives an overview of the current discourse surrounding the occupation of care aiding in LTRC. The key issues discussed that relate to care aides include: (i) education; (ii) scope of practice; (iii) position within the hierarchy of healthcare; (iv) their role as dementia carers; (v) retention, turnover, and burnout; and (vi) their participation in research. To begin, it must be made clear that although care aides are invaluable members of the healthcare workforce, the discourse surrounding the details of their job and their perceptions of their role within LTRC is limited (Ginsburg, 2015; Castle et al., 2007). Even compared to residents, care aides are thought to be the least-researched population in LTRC settings (Wei et al., 2015). Most research that is conducted in healthcare institutions has been shown to have very little focus on, or even not to have included, unregulated healthcare staff members such as care aides. For example, in her 2014 thesis, Caspar found through a review of the literature on interdisciplinary collaboration, team decision making, team building, and communication in healthcare institutions that the studies focused almost exclusively on regulated healthcare professionals (e.g., registered nurses, licensed practical nurses), with little or no mention of attendants, assistants, or aides as members of the healthcare team. Also, research about care aides does not actually incorporate their voices and instead focuses on management's perspective of care aides in LTRC. Research that does include nonprofessional workers such as care aides reveals that they often feel vulnerable in their employment and therefore may be less likely to speak out or even participate in research (Sims-Gould et al., 2010).

Detailed, accurate information on the current state of care aides in LTRC is sparse. What is known is that in Canada care aides constitute a significant component of both home and community care as well as the LTRC sectors of the healthcare labor force. They provide up to 80% of direct care to those living in LTRC (Caspar, 2014, and thus may have the potential to have the biggest impact on resident quality of life (QoL). Unfortunately, the exact size of this workforce at the national level is not known (Berta, Laporte, Deber, Baumann, & Gamble, 2013). One reason that makes the precise logistics of this group difficult to find is that care aides go by many names. In Canada alone, the title of the care aide role changes from province to province. In British Columbia, they are called health care aides or residential care aides; in Ontario, personal support workers; in Nova Scotia, continuing care assistants; and in the United States, nurses' aides or certified nursing assistants (Berta et al., 2013; Rakovski & Price-Glynn, 2010). The term *care aide* is also used synonymously with other titles that are healthcare setting-dependent, including healthcare aide, long-term care aide, nurse aide, nursing attendant, orderly, patient care aide, patient service associate, personal care attendant, or resident care aide (Government of Canada, 2016). The following section reviews the current role of care aides within LTRC in Canada.

Care Aide Role

Although care aides deliver the most direct care to LTRC residents, they are an understudied work group (Caspar et al., 2016; Castle et al., 2007; Cooper et al., 2016; Estabrooks et al., 2015). Knowledge about care aides' work attitudes and intentions is key to recruitment programs, incentive systems, and retention/training strategies for these vital members of the healthcare team (Ginsburg et al., 2016). What is known is that the issue of care aide absenteeism is associated with poor performance on key quality indicators (Castle & Ferguson-Rome, 2015). Care aides have a unique insight into the lives of service users and those factors that may impede or enhance the delivery of high-quality dementia care (Talbot & Brewer, 2016). Their work environment is challenging, with high rates of aggression from residents (Zeller et al., 2009). In fact, almost half of Canadian care aides in LTRC experience violence daily or almost daily (Daly, Banerjee, Armstrong, Armstrong, & Szebehely, 2011).

Care aides work under the direction of a registered nurse (RN) or licensed practical nurse (LPN) (Berta et al., 2013). Care aides do not have a regulated scope of practice, which describes the procedures, actions, and processes that a healthcare practitioner is permitted to undertake in keeping with the terms of their professional license. Because care aides are neither licensed nor monitored by a regulatory body, they are without a legally defined scope of practice. Due to this, there is currently no clear understanding of the roles and responsibilities that care aides have. Instead, care aides have a core competency profile, which establishes a set of competencies (knowledge, skills, behaviors, and attitudes) that care aides are expected to possess as an outcome of their baseline education. These competencies reflect the minimum standards required to ensure that care aides provide the public with safe, competent, and ethical care. Until recently, care aides in Canada fulfilled purely supportive roles, assisting with activities of daily living such as bathing, dressing, meal preparation, or "light" household tasks. However, LTRC residents increasingly need more complex care (Williams et al., 2009). Workforce shifts and the growing complexity of care have led to the role substitution and expansion of care aides. For example, some care aides are now delegated tasks such as catheterization and injection (Berta et al., 2013).

A study conducted by Woolrych and Sixsmith (2013) examined the experiences of formal carers in the United Kingdom (the equivalent of care aides in Canada) working within an integrated dementia care service provider called CareConcepts. They found that the delivery of flexible services required that formal carers be given the freedom to make changes in their everyday workload to better manage their cases and maintain a high quality of care delivery. They also found, however, that delivering flexible and responsive services to accommodate the changing needs of residents created additional mental and physical demands for the carers, including "longer working hours" as well as a feeling that they were "always on duty." To facilitate this, the care provider must transfer power and autonomy to the formal carers themselves, enabling them to make the decisions they need to and as they see fit, or "on-the-fly," as the authors suggest. However, to achieve this, as Woolrych and Sixsmith (2013) elaborate, the formal carers must be comfortable with taking on this extra level of responsibility, which they may not be prepared to do within their current role and salary, and the organization must be willing to transfer full control and power to the individual carers, which it may be reluctant to do. In this way, both the LTRC facility as well as the care aides must be empowered in allowing the care aides to have greater responsibility in caring for residents.

In Canada, care aides are unregulated and are not recognized as a profession in both home and community care as well as in LTRC settings (Berta et al., 2013). The Health Professions Act does not cover care aides and therefore does not regulate them. The Ministry of Health sets out legislation to cover professionals. In comparison to care aides, RNs have their own college that regulates, governs, and mandates their scope of practice. Care aides do not have their own college or licencing body. Therefore, if a care aide does something dangerous or something they are not trained to do, it will fall under the nurses' license. Although care aides are not technically “professionals," their curriculum does cover “professionalism.” There is no consensus in the published literature about care aides as to whether their role within LTRC should be deemed professional (Berta et al., 2013), or if they should be labelled instead as *“nonprofessionals”* (Squires et al., 2015).

As previously discussed, the LTRC population has changed from what it was in the past, with residents being more frail when entering and requiring more complex care. The current training for care aides has not kept pace with the changing needs of residents (Kayser-Jones, 2003). There is tension between the activities care aides can perform in LTRC, which are structured by union contracts and other policy documents, and the actual care that they would like to deliver. This draws attention to the relational versus ask-based tension care aides experience in providing care in LTRC. In her doctoral thesis, Caspar (2014) found that although care aides provided 80% of care to residents in all four LTRC sites she studied, they lacked practical access to the institutional texts that contained important information relevant to the residents’ individualized care needs and preferences (e.g., assessments, care plans, social histories). Casper also found that care aides primarily received and shared information verbally; however, the organizational systems in the facilities studied mandated the written exchange of information and did not formally support a verbal exchange. Consequently, the verbal exchange of care information was largely dependent upon the quality of the care aides’ working relationships with one another and especially with management (Caspar, 2016).

Care Aide Education

Research over many years has presented evidence to suggest that elderly people are generally devalued by a youth-orientated culture (Matzo & Goetschius, 1993). Slevin (1991) expressed concern about the existence of ageism and its implications for nursing and caring occupations. Research has shown that ageist beliefs are consolidated rather than dissolved during healthcare training (Stevens & Crouch, 1995). The reason negative perspectives are further increased and cemented during a nurse’s education is not because of the curriculum component of the courses, but rather the entirety of the courses (Bednash, Mezey, & Tagliareni, 2011). The professional socialization of nursing education appears to carry messages that devalue personal care duties and value technical care. For example, prestige is given to activities attached to all levels of medical technology or technological care and not to personal care duties or basic care. Because working with older patients requires so much hands-on care, it is located well outside the areas of work that are viewed by nurses to include clearly focused professional pathways.

A study conducted by Gallagher and colleagues (2006) assessed the attitudes of healthcare personnel in hospital settings. Their findings show significant differences in negative attitudes between assistant personnel and nurses versus negative attitudes between porters and nurses. They found that the assistant personnel believed that older adults complained and were irritable, grouchy, and untidy. Practice area had no influence on attitudes; attitudes were, however, significantly predicted by education levels. Findings suggest that irrespective of setting, assistant personnel, such as care aides and porters, possess significantly greater negative attitudes toward older adults than nursing staff (Gallagher, Bennett, & Halford, 2006). Although this study was conducted in the United Kingdom and the setting was hospitals and not LTRC, these results are replicated in the literature in LTRC settings. Various studies examine the role of staffing levels, turnover, and staff–resident interactions when analyzing outcomes linked to resident quality of life and quality of care (Munroe, 1990; Bravo et al., 1999; Svarstad et al., 2001). While the literature echoes the fact that staffing issues are a recognized perceived barrier to the promotion of positive outcomes in LTRC, less is known about the perceptions and experiences of care aides regarding the barriers and facilitators in their care delivery.

It appears that the first 6 months of employment are critical. A study conducted in the United States of certified nursing assistants (CNAs, the equavilant of care aides in Canada) cited pay as a reason for leaving LTRC; better pay, however, was not a distinct characteristic of the jobs taken by the CNAs who left. This study highlights the importance of the first 6 months of employment to retention (Meyer, Raffle, & Ware, 2014). Regarding care aide compensation, a study conducted by Laxer et al. (2016) reviewed and compared the work-related characteristics of assistive personnel (care aides) in LTRC in five countries (Canada, Germany, Norway, the United Kingdom, and the United States), Financial compensation for assistive personnel in Norway and Canada is greater than in the other countries.

Care Aides within the Hierarchy of Healthcare

Caring labor is seen by many authors to be central to care aide job satisfaction in LTRC (Burgio, Fisher, Fairchild, Scilley, & Hardin, 2004; Rakovski & Price-Glynn, 2010; Stacey, 2005). The concept of caring labor refers to jobs that require emotional and physical caring in personal, enduring, and constructive relationships with clients (England, 2005; Himmelweit, 1999). A more comprehensive understanding of the complexities of caring labor will provide a more holistic view of the care aide experience (Rakovski & Price-Glynn, 2010). Also, the care aide's job performance is likely to have a huge influence on the residents' quality of care.

A 2010 national survey was conducted of data from the 2004 Centers for Disease Control and Prevention's National Nursing Assistant Study (NNAS) of 3,017 nurses' aides (NA; the equivalent of care aides in Canada) working in LTRC facilities across the United States. The NNAS results confirm the importance and centrality of caring in NAs' work. NAs motivated by caring for others were significantly more satisfied with their jobs than those motivated by other reasons, such as convenience or salary. Overall, NAs reported high job satisfaction, particularly with learning new skills, doing challenging work, and organizational support for caring labor. Areas of dissatisfaction were salary, time for reproductive labor, and turnover. Intersectional analysis revealed that race and citizenship played a stronger role than gender in worker satisfaction (Rakovski & Price-Glynn, 2010).

Care Aides in LTRC as Dementia Carers

Intertwined: Care Aide and Resident Quality of Life

Previous ethnographic work in LTRC (including the works of Diamond, 1995; Foner, 1995 and Gubrium 1997) established that there were no absolute angels or demons regarding care staff. Diamond's (1995) first hand report on the work of nurses and other care-partners in LTRC is set powerfully in the context of wider political, economic, and cultural forces that constrain and shape the quality of care for the residents in these settings. His work it is one of the few early ethnographies that critically examined the lives of direct care workers, the care aides. Foner's Foner's (1995) analyzes the tensions and contradictions in nursing home bureaucracies. She focuses on the ways in which individuals were socially constructed and positioned were often historically situated within the intersections of race, class, and gender, the relations of power, and examples of resistance, all of which reflect the complex dynamics of bringing together, sometimes unwillingly, people from multiple different backgrounds to live and work together in the same space (Baumbusch, 2011). In Gubrium's classic 'Living and Dying at Murray Manor' (1997) he describes how the 'work' in LTRC is conducted. His research reveals how staff, residents, family members, physicians, and funeral directors negotiated their respective roles, needs, and goals - and how, in the end, Murray Manor, the LTRC facility, emerged as an organized social entity. Taking these foundational pieces of work into account, the intersection between the well-being of staff and residents in LTRC is inseparable.

In the previously mentioned historical ethnographies it as been well established that the quality of life (QoL) for vulnerable residents in LTRC is highly dependent on the well-being and continuity of their care aides (Kinjerski & Skrypnek, 2008). The complex behavioral problems of residents with dementia may cause significant impairment of their social or occupational functioning and can place a tremendous burden on care aides in LTRC settings (Porth, 2004). Care aides are often the care partners within LTRC that have the least formal education but the most hands on responsibility for residents (Liu, 2007). Providing care for residents with dementia is often difficult due to this population's declining verbal abilities and related challenges (Kaasalainen, Brazil, Ploeg, & Martin, 2007). Healthcare workers' perceptions and reactions can exacerbate difficult behaviors and lead to an increased social distance between residents and care aides (Kinjerski & Skrypnek, 2008). In some cases, residents in LTRC may get the "care" they need in the form of medication or bed transfers, but they may not get "care" in the form of social interactions and individualized care.

Unprepared care aides may not only experience exhaustion and mental distress, but also physical altercations with difficult or desperate residents (Shinan-Altman & Cohen, 2009). In residential care, being struck or grabbed is the second most common cause of occupational injury after overexertion (Worksafe British Columbia, 2010). A general lack of adequate training, education, political will, and administrative support all contribute to the underreporting of aggression against care aides (Henderson, 2009). A resident with a reputation for violence and aggression may be avoided by members of the nursing team and thus not receive adequate PCC or RCC, which will negatively impact the resident’s QoL.

Although the importance of individualized care is highlighted both by care aides and residents, there is limited research that examines the perceptions of individualized care, especially in LTRC settings (Suhonen, Alikleemola, Katajisto, & Leino-Kilpi, 2012). Merely increasing compensation is not enough to attract and retain employees; the work itself must be made more rewarding (McKenna, Hasson, & Keeney, 2004). Care aides in LTRC who see their work as meaningful tend to experience increased satisfaction with their work and are more likely to stay in the profession and deliver high-quality care (Suhonen et al., 2012).

On the Job: Retention, Satisfaction, and Burnout

The people who care for and interact with residents daily become the focus of residents’ relationships (Thomas, 2003). Unfortunately, some care aides in LTRC are treated as if they are interchangeable in being moved along from one unit to another and with the value of their relationships with residents going unrecognized. Furthermore, care aides have historically reported being poorly cared for by employers. Caring, warm-hearted people are attracted to the job, but when they are treated poorly, they leave (Thomas, 2003). Without some means of having their efforts recognized and appreciated, long-term, permanent care aides may become frustrated and over time burnout. A study conducted by Cherry and colleagues (2007) examined job satisfaction and the regulatory environment among care aides in LTRC. They found that even without regulations, the goal of care aides was to provide quality care because of a commitment to their residents and their community as well as a genuine desire to care for the residents. Interestingly, LPNs and RNs reported sometimes spending 40%-90% of their workday on paperwork and not on direct care for residents. One suggestion this article gives to alleviate some of the time care aides spend on paperwork is in the use of information technology (Cherry, Ashcraft, & Owen, 2007). Rai (2010) conducted a review of burnout in care aides in LTRC and found that the rates of burnout for care aides are significantly higher than for most other healthcare settings. Burnout has been found to be associated with psychosomatic diseases, motivation and commitment, job satisfaction, turnover, absenteeism, citizenship behavior, and job performance (“Burnout in Organizational Life,” 2004). The findings indicate that workload, role conflict, and stress were strong predictors of emotional exhaustion and depersonalization for all healthcare workers in LTRC. The findings suggest that if LTRC facilities want to reduce burnout, particularly in terms of emotional exhaustion and depersonalization, they should make reasonable work demands and develop strategies to reduce role conflict and stress. Regarding care aides, the amount of negative discourse around their role in LTRC is staggering, from low job satisfaction (Squires et al., 2015), to burnout (Cooper et al., 2016), abuse (Boye & Yan, 2016), and workplace bullying (Chamberlain, 2016). Thankfully, there has been an increase in literature focused on the positive discourse surrounding working as a care aide in LTRC. As previously discussed, the role of care aides is increasing in importance due to the aging population and greater predicted reliance on LTRC. There is a need for more training and support to improve the work capability of care aides. The hope is that in the future the job of care aides can be increasingly looked at as a career so that these individuals are no longer treated as hourly workers. Changes need to be made to ensure greater job satisfaction for care aides or we run the risk of increasing numbers of care aides showing dissatisfaction through poor performance, burnout, work absences, and high rates of turnover (Liu, 2007).

As previously stated, the lack of desire to work in LTRC by care aides is cyclical in nature. Research has supported the notion that care aides at all levels have a negative view of working with older adults, and societal stereotypes concerning older adults influence and propagate these negative views prior to and during care aide training (Stevens & Crouch, 1995). It is undeniable that healthcare work can be difficult and frustrating, especially when dealing with a unique population such as older adults with dementia in LTRC (Kinjerski & Skrypnek, 2008). Often new healthcare workers are not adequately trained to work in these complex care environments. The culture of care and structural issues within the LTRC facilities are such that they lead to care aides being unable to deliver the quality of care they want to deliver. This leads to burnout and low job satisfaction and proliferates a general lack of interest on the part of new care aides to seek employment in LTRC settings, which also leads to a paucity of adequate care delivered to residents in these facilities. A greater understanding is needed from the perspective of care aides working in LTRC regarding their experiences. Hearing the voices of care aides will lead to a better understanding of the nature and reality of delivering care in LTRC. And from this knowledge, the facilitators of and barriers to delivering care to residents may be better understood.

The following section reviews the guiding theoretical approaches that were used in this study.

Care Aides Involvement in Research

A 1998 study conducted in the United States investigated certified nursing assistants' (CNAs; the equivalent of care aides or personal support workers in Canada) perceptions of incontinence etiologies, as well as perceived barriers to implementing prompted voiding in long-term care (Lekan-Rutledge, Palmer, & Belyea, 1998). As suggested by the title, "In Their Own Words: Nursing Assistants' Perceptions of Barriers to Implementation of Prompted Voiding in Long-Term Care," no care aide was spoken to regarding her perspectives on the limitations and barriers to this (at the time) new procedure. Instead, a questionnaire was administered to CNAs in 23 long-term care facilities. The researchers found that the CNAs perceived inadequate staffing, workload, and turnover and absenteeism as barriers to implementing the procedure. The CNA recommendations from this study for long-term success included increased staff and staff support, improved communication, ongoing education, and alternative models of care delivery. The literature appears to emphasize including those living with dementia in LTRC and not those who are working with residents who have dementia. Arguably, both sides of the discussion (those living with dementia and those caring for them) must be represented to accurately develop and implement viable solutions to the issues at hand.

2.4. Guiding Theoretical Approaches

There was not one singular approach that would provide a sufficient theoretical foundation for this qualitative study. Instead, this study drew on a range of perspectives that link critical and social theory with institutional and social aspects of aging to address the research objectives. Although there are many theories that would help facilitate and guide the understanding of the reported experiences and perspectives of care aides, this study focused mainly on critical gerontology and institutional theory. Together, these critical perspectives provided a valuable lens for considering the relationship between personal, interpersonal, and organizational systems within LTRC to explore care aides' experiences and perceptions.

Critical Gerontology

Critical gerontology (CG) is an approach to understanding aging that considers issues of power and control in contemporary society alongside the constructions and deconstructions of aging (Moody, 2008). CG has been said to serve the necessary role of casting a critical eye on society and the field of gerontology itself (Ray, 2008); it unpacks the underlying assumptions that exist concerning how and why we do things. The theory examines the place and status of older adults in society and plays an important role in engaging us with the wider socio-cultural (or socio-political) and structural factors that shape an individual's experience of aging, an experience that goes well beyond the presence of the physical aspects of aging (Innes, Kelly, & McCabe, 2012). CG is concerned with the emancipation of older people from all forms of oppression (Moody, 1993). Mainstream gerontology espouses that research, practice, and policy all work together for the benefit of older adults. But CG takes a step back, looks at what is occurring with a critical eye, and points out the hidden interests, conflicts, and contradictions that lie behind the status quo. CG does not need to promote hostility or arguments, but rather is oppositional and deliberately raises uncomfortable questions about the hegemony of theory and methods that are prominent in mainstream gerontology (Moody, 1993). CG arose, at least in part, in opposition to the conventional "social problems" approach to aging, which views aging as a problem that must be fixed (Moody, 2008).

Research and Critical Gerontology

CG draws on both the personal experience of older adults as well as their relationship to social and structural inequality to create a radical approach to aging (Biggs, 2008). It argues that the nature of scientific data cannot be separated from the approach, interest, orientation, and other subjective aspects of the researcher. Moody (1993) describes how we must be careful not to fall into the trap of viewing human beings as mere variables who hold statistical values; people are more than vessels of experience.

> “In recovering a human dimension in the study of aging, we will recover something important about ourselves. When we finally come to look into the ‘human face’ of gerontology, we will understand at last that the face we see is simply our own.” (Ray, 2008, p. 295)

This quote emphasizes that personal refection should be central to the progressive agenda of CG; as critical gerontologists, we must do our best to personally reflect on the aging experience. We are examining something that is currently distant to where we are at present, yet it is not so distant that we cannot be reflexive and identify with that position. Briggs (2008) argues that instead of empirical research examining *“What is going on?,”* the existential questions related to adult aging and the social challenges that come along with them should instead examine *“How can we make things better?*” In other words, the existing situation has been taken as a given and we are now working to make things better. Hopefully, with the further awareness of critical gerontology’s position on the part of aging researchers, there will be a greater focus on the issues of power that underpin all critical approaches. A greater focus on the issues of power is needed because, although aging affects everyone, the issues of care and aging affect marginalized populations—those with less power—more than those who have more power. There is a clear power differential in aging experiences.

Institutional Theory

LTRC has remained a prominent support system of caring services for older people throughout the modern period, despite strong examination and scrutiny over the last century. This section summarizes and critically evaluates two prominent theories that have been used to understand the nature and experience of institutional care for older people: Michael Foucault’s critique on institutions and Erving Goffman’s analysis of total institutions. This section also relates Foucault and Goffman’s institutional theories to current research to highlight why these theories are indeed valuable to this thesis.

Both theorists discussed the topic of institutions and drew conclusions that demonstrate the role of institutions on macro and micro levels. Foucault investigated the former using a post-modern lens, whereas Goffman, a symbolic interactionist, examined the latter. Although Foucault and Goffman conducted most of their work in prison and asylum settings, their theories of institutions are compared here in relation to their merits and limitations in the context of long-term institutional care for older adults. The key concepts discussed are *power* (including a discussion on surveillance and discourse) and *total institutions* (including institutionalization of both residents and care aides).

Power in Long-Term Residential Care

According to Foucault, power is a relationship between people in which one affects another's actions (Foucault, 1977). Power is present in all human relationships and penetrates throughout society. Foucault saw society as a huge web, with much of the power tending to be concentrated toward the higher echelons of society (Foucault, 1975). In this web, power flows simultaneously in different volumes and directions according to the various forms of “power relations” in the “network” of power exchange. In the LTRC setting, power is perceived as unidirectional, enforced by those at the top of the hierarchy (management) down to those at the bottom (residents) (Kelson, 2013). The key factors involved in caring for residents in LTRC are structured within an established hierarchy where a small group of the managerial team is positioned at the top, followed at the bottom by registered nurses, allied health professionals, licensed practical nurses, and care aides.

Foucault paid attention to the relationship between power and knowledge in institutional settings (Foucault, 1975). Since knowledge is power, knowledge is also social capital. Foucault’s web of power and knowledge outlines residents’ health, safety, well-being, and quality of life, all of which rely on the relational knowledge and care that care aides provide to residents (Martin, 1982). In LTRC settings, the care aides have knowledge that residents and their family members rely on, and thus they have a certain amount of social capital and power (Koehn, Kozak, & Drance, 2011). Yet, care aides often rely on RNs and LPNs to have access to specific task-based information they need regarding the residents they care for, and in this way it may be seen that in the established healthcare hierarchy care aides have the least knowledge and thus the least amount of power within the established LTRC hierarchy of care providers. As will be described in greater depth later in this Chapter 6, care aides have no opportunities for mobility within their role in LTRC. Once a person becomes a care aide, she is not able to be promoted or demoted to another role within LTRC without further education and credentials, no matter their experience level. In the web of power found within LTRC, it has been argued that those who hold the least amount of power are the residents themselves (Kelson, 2013), although, as will be described in Chapter 7, it could be seen that both residents and care aides equally hold the least amount of power in LTRC.

Total Institution

Goffman's (1961) description of institutional life and its demoralizing impact on the individual remain influential in research devoted to improving life in LTRC, which unfortunately continue to evoke images of confinement and a loss of control and privacy. The central feature of a total institution (TI) can be described as a breakdown of the barriers ordinarily separating the three main areas of one's life: sleep, play, and work. Regarding LTRC, Goffman stated that this type of institution was established to care for persons felt to be both incapable and harmless (Goffman, 1961). Foucault would eventually point out that even Goffman's description of residents in LTRC used discourse that evokes a picture of unproductive and unneeded members of society.

There are four aspects to TI that Goffman (1961) defined: (i) all aspects of life are conducted in the same place under the same authority; (ii) every daily activity is carried out in the immediate company of a large batch of others, all of whom are treated alike and are required to do everything together; (iii) all phases of the day are tightly scheduled and imposed by the governing authority; and (iv) all scheduled and enforced activities are a part of a master plan that has been pre-designed to fulfill the official aims of the institution.

Goffman's four aspects of TI are evident when it comes to residents in LTRC. First, all aspects of older adults' lives in LTRC are conducted within the walls of the facility. Residents sleep, eat, and conduct any work or recreational activity inside the facility where they live. Second, residents conduct all of the main aspects of their life with their fellow cohort of residents. Often the only change in members of their cohort comes from individuals who are newly admitted to the facility, such as short-term or respite residents and when a resident dies. Third, all phases of a resident's life are conducted within a strict schedule enforced by the care aides. The tightly run schedule in long-term care ensures that the care aides can feed, clean, and care for all residents within their allotted work shifts. The fourth and final aspect of Goffman's concept of TI applied to LTRC is that the enforced activities are a part of the master plan. The "master plan" for current LTRC settings is difficult to decipher. From a CG perspective, it could be argued that the master plan for keeping older adults in LTRC is a form of domination (Moody, 2008). One could argue from this critical perspective that LTRC is the warehousing of older adults until they die because they are no longer productive members of society. Residents in LTRC are not participating in the workforce and thus are not productive members of a capitalistic society. Also, residents in LTRC predominantly have cognitive impairment issues, such as dementia, that may make them appear as “awkward” individuals in a society who are easier dealt with if they are filed away, out of the public’s sight (Barry et al., 2008). A human is a human until a few minutes after a person draws his or her last breath (Power, 2014), and as such we have a social contract to care as best as possible for those who are at the very last stage of life. In doing so, we must also as best as possible take care of those whose careers are devoted to caring for this vulnerable population.

2.5. Purpose and Significance

The current study is significant because it explored the perspectives of care aides employed in LTRC, one of the most marginalized populations in healthcare in one of the most under researched healthcare settings. This study adds to the body of knowledge surrounding LTRC through the unique perspective of care aides, who are the least researched members of the healthcare team, yet they are the most closely involved with the direct care of residents in LTRC. This study was designed to gain a better understanding of the experiences and perspectives of care aides while also helping to amplify their voice within gerontological research. Using the knowledge generated from the reported perspectives of care aides, a list of emerging issues was created. These issues include suggestions on how to make the working conditions better for care aides and to facilitate their delivery of care to residents. The information garnered from this study will contribute to the culture change movement in LTRC by developing a more complex understanding of what the experiences and perspectives of care aides are and how LTRC institutions can better support this invaluable population of healthcare workers.

Chapter 3 reviews the methodology that was chosen and implemented in order to examine care aides’ experiences and perceptions in LTRC.

Chapter 3. Methodology

The purpose of this research was to explore the experiences of care aides employed in LTRC, as well as their perceptions of the barriers and facilitators in the delivery of care to residents. The goal of this study was to gain a better understanding of the experiences and perspectives of the largest proportion of people who are employed in LTRC settings and who provide most of the direct care to residents—the care aides. This chapter is divided into the following sections: (i) research questions; (ii) methodological approach; (iii) research design, including the informal advisory group, description of setting, study site, and participants; (iv) data generation methods; (v) data analysis and interpretation; and (vi) a discussion of the ethical considerations, including trustworthiness.

3.1. Research Questions

One main research question and three sub questions guided the creation of the study design, data collection, and analysis. These questions were:

1. What were the care aides' experiences leading up to and prior to entering LTRC as a care aide, especially during their education and trainng?

2. What relationships do care aides have within LTRC, including relationships with residents, family of residents, staff members, management, and the union.

3. How do care aides feel society perceives their role in LTRC?

4. What are care aides' perceptions of the barriers and facilitators in their delivery of care in LTRC?

The objective of these research questions was to acquire information about the experiences and perceptions of being employed as a care aide in LTRC to articulate the experiences of being employed as a care aide in LTRC. From the accounts of the care aides who participated, this study the commonalities, differences, and uniquenesses of their perceived role in LTRC.

3.2. Methodology: Qualitative Design

A qualitative methodology was appropriate to achieve an in-depth understanding of care aides within LTRC, drawing from ethnographic methods for data collection. Qualitative research, is typically inductive (Creswell, 2013), reflexive, and shaped by the researcher's own experiences in collecting and analyzing data. Creswell (2013) explained that the logic a qualitative researcher follows is inductive, flowing from the ground up and not necessarily passed down from the perspectives of the person asking the questions or from pre-established theory. In qualitative research the focus is on an emic perspective, or the views of the people and their perceptions, meanings, and interpretations (Savin-Baden, 2013). As such, this type of investigation focuses on understanding people and their circumstances by considering how people see the world and make meaning of it. A qualitative methodology helps researchers understand individuals, cultures, and other phenomena rather than analyze relationships between variables or test cause-and-effect relationships. Qualitative researchers acknowledge multiple constructed realities and recognize that individuals have different perceptions of reality and at least to some degree construct the realities in which they live (Savin-Baden, 2013).

In qualitative research, the researcher often identifies and articulates a philosophical stance that ultimately guides the researcher's philosophical position. Philosophical frameworks specify the assumptions that organize the research (Savin-Baden, 2013). At the most basic level, paradigmatic questions are concerned with ontology, which are views of the nature of reality (what aspects of reality do we think are worth examining) and epistemology, which are views of the relationship between the knower and what can be known (what counts as knowledge in our modes of inquiry). With respect to research, a paradigm is essentially a worldview, a framework of beliefs, values, and methods within which research takes place. It is this worldview within which researchers work.

At a fundamental level, personal stance can affect a researcher's views of research context and participants, a process that is connected inherently to the notion of bias. Bias is a preconception about a thing, person, or group. It means a researcher holds a preferential perspective at the expense of (possibly equally valid) alternatives. This also means that biases can cloud researchers' judgment and lead them to see what they expect or what they want to see, which may or may not be what the data suggests (Salvin-Baden, 2013). In short, the concept of bias highlights the apparent dangers of the old adage in research *"you ain't gonna learn what you don't want to know"* (Adams & Sardiello, 2000) (which is also expressed in the lyric *"you ain't gonna learn what you don't want to know"* (from the Grateful Dead song "Black-Throated Wind" [1972]).

The worldview that was taken for this study was constructivism, which draws from psychological work and holds that people develop individual perspectives of the world through their experiences in it, including social experiences. The meaning and shared knowledge of individuals are developed through their interactions in the world they live. In constructivism, individuals seek understanding of the world in which they live and work (Charmaz, 2006; Creswell, 2013). Individuals develop subjective meanings of their experiences, which are directed toward certain objects or things. With a social constructivist worldview, the research looks for the complexity of participants' views, rather than narrowing the meanings into a few ideas or categories. In social constructivism, the researcher does not necessarily start with a theory, but instead generates or inductively develops a theory or pattern of meaning by relying on the participants and their interactions with others, as well as by understanding the historical and cultural norms that operate in the individuals' lives. Therefore, the goal of research is to put as much emphasis as possible on the participants' views of the situation (Creswell, 2013), and in the case of this study the emphasis is on the care aides' view of their experiences within LTRC.

Data was generated from this study using an ethnographic approach, including the following methods: (i) semi-structured interviews; (ii) naturalist observation; and (iii) reflexive journaling. Ethnography as an approach is the study of people, cultures, and values. An ethnographic approach aims to create an understanding of those being studied and requires intensive fieldwork to gain a comprehensive and detailed view of a social group and its setting. Although there are numerous types of ethnography, they all share the same general key characteristics (Savin-Baden, 2013). Ethnographic researchers focus on everyday life rather than the unusual or peculiar, and, in general, ethnographic researchers seek to understand what is “normal” within the research context and immerse themselves in a particular setting, spending a significant amount of time with those they are studying. Key ethnographic data generation methods involve the use of participant observation as a primary method, facilitating the notion that through participation in a community it is possible to come to understand it better. Unstructured and in-depth data generation allows the ethnographic researcher to use the data to undertake comprehensive interpretations of the meaning and action of those observed (Creswell, 2013). Ethnographic studies also present findings, to the best of the researcher’s ability, from the participants’ point of view. Traditionally, ethnographic studies attempt to understand and articulate a culture from the perspective of its members. The use of ethnographic methods was the most appropriate choice for data generation because this study was focused on the perspectives and experiences of care aides in LTRC, and all data generation took place within the LTRC setting.

Qualitative research occurs in a natural setting of people whose experiences are the object of an explorative research paradigm and its assumption (Guba & Lincoln, 2005). Description is the bedrock of qualitative reporting (Patton, 2015), and by using a qualitative approach this study was able to describe the experiences and perspectives of the care aides who participated in this study. The sections that follow describe the research design—starting with the creation of the informal group of advisors and moving on to the setting, sample (n = 31), and study site—as well as outline how access to the study site was gained and the participant recruitment process.

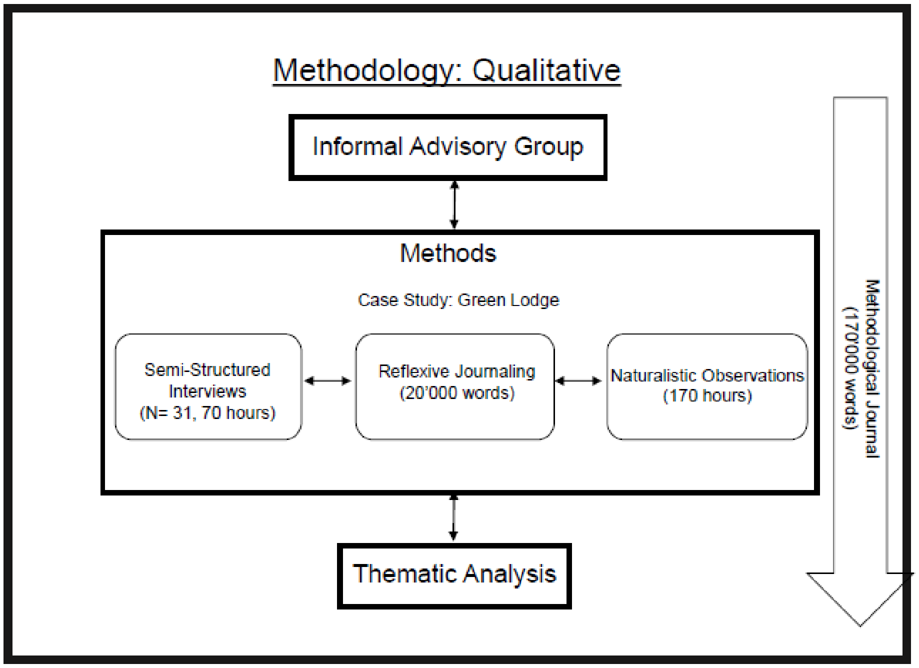


Figure 3.1. The following figure outlines the methodology and study design followed during this thesis.

The first step in the design of this study was to create a group of informal advisors comprised of key stakeholders in LTRC. This group included two engaged members of the management team at the study site (General Manager and Recreation Therapy Manager), the doctoral supervisory committee, and three mentors (a highly qualified professor emeritus with five decades of experience researching aging issues; an older adult woman who lived in a neighboring town to the study site and for her entire life had lived with an often-debilitating chronic illness. These two mentors originally began as a required component of an Interdisciplinary Fellowship from the Canadian Frailty Network (2013–2015). However, after the funding had stopped and the requirement had been completed, these two relationships were seen to be an invaluable aspect of understanding the participants, the experiences and perceptions they shared, and the implications these had on the findings. With their permission, these two mentors were involved throughout the duration of this project. The third mentor was a retired care aide who had previously been employed in LTRC facilities in “Old Town” (name changed to protect anonymity). Members of the informal advisory group were consulted before each section of the study was implemented as well as when issues came up during research design, data collection, and analysis.

3.2.1. Setting

Ethnographic research occurs in a natural setting of people whose experiences are the focus of exploration. Where and when the research takes place are critical factors for qualitative research itself. Understanding the context is critical to understanding the meanings that individuals communicate. There is a sense of collaboration with people rather than treating them as subjects, and researchers acknowledge the ways in which they see participant roles and their reasons for deciding how participants are involved in the research (Savin-Baden, 2013).

Community: Old Town

To give context to the location of the study site, Old Town is a small town of less than 9’000 residents in a more rural area of British Columbia (Government of Canada, 2012). Land development in the Qualicum area did not begin until the late 19th century. The Hudson's Bay Company established Old Town’s closest city in 1852. In 1894, a road was extended to Old Town from a neighboring town, and in 1914 the railway also reached Old Town. This town is currently both a popular tourist destination and a retirement community. The median age of Old Town is 65 years, and in 2011 nearly half (47%) of the population was older than age 65 (Government of Canada, 2012). The advanced age of the population of Old Town allows for a unique insight into what the future of the rest of Canada’s aging population may look like.

Study Site: Green Lodge

Located in the heart of Old Town and founded in 2006, Green Lodge is a campus of care facility that houses approximately 230 residents and employs another 220 individuals, 79 of whom are care aides. Green Lodge is one of the largest employers in all Old Town. It is an aesthetically pleasing, four-story building with views over their award-winning gardens, the ocean, the mountains, and the town centre. Green Lodge offers several lifestyle options, including independent living, assisted living, which are privately funded only, and complex care, which is both public and privately funded by the health authority and private pay. In their advertising, Green Lodge boasts of offering many different "lifestyle options." Residents choose the lifestyle option that currently serves them best and, when necessary, they may progress through the different levels of care in one convenient location. Organized in order of least to most care, the breakdown of the four different lifestyle options that Green Lodge offers are as follows:

1. 39 privately owned condos
2. 67 independent living suites for single or double occupancy
3. 30 health authority–funded assisted living beds
4. 86 health authority–funded complex care beds
5. 11 private pay and respite beds

The residential care facilities at Green Lodge provide 24-hour professional care and supervision to adults in a supportive, secure environment. This includes publicly subsidized residential care services that are available to adults with complex medical and cognitive care needs as well as an assessed and urgent need for 24-hour care. In its advertising, services at Green Lodge are described as being aimed toward meeting the complex health needs of those admitted to a facility and include: accommodation; 24-hour nursing care; other professional services such as nursing, physical therapy, social work, and nutritional support; hospitality services (meals, housekeeping, recreational activity programs, emergency response); personal care assistance; and end-of-life care (Residential Care Services, 2013). Unlike most LTRC facilities in Canada, most of the care aides in Green Lodge are Caucasian, which is unusual in terms of the limited number of ethnically diverse care aides seen in larger municipalities. Interviews conducted for this study took place with care aides who worked in the complex care floor of this facility. Care aides were chosen from the complex care floor because most of the care aides employed at Green Lodge work on that floor and it is the closest replication of what other LTRC facilities look like in the rest of Canada in comparison to the other three floors.

The study site, Green Lodge (name changed to protect anonymity), is an LTRC facility located in Old Town, a rural town on Vancouver Island in the province of British Columbia, Canada. The rationale for choosing Green Lodge is that it offers a unique and valuable view inside an LTRC setting within an already increasingly aged population. As described in Chapter 2, Canada's population is aging, and the demographic makeup of

Old Town, with a mean average age of 65, accurately reflects the aging population of Canada that is projected in the very near future. The names of the town and LTRC facility were changed in this thesis in accordance with Simon Fraser University's ethics regulations.

3.2.2. Gaining Entry

Negotiating entry and becoming immersed in the day-to-day milieu of Green Lodge was key to successfully engaging in data collection (Savin-Baden, 2013). Invested commitment from Green Lodge was formed based on the researcher's pre-established volunteer and advocacy roles within Old Town. In a study that uses ethnographical data-generating methods, access typically begins with a "gatekeeper," an individual who is a member of or has insider status within a cultural group (Creswell, 2013). For this study, the gatekeeper was Green Lodge's General Manager, who agreed to cover the care aides and pay for their time participating in this study because she believed in the importance of understanding, from the care aide perspective, the barriers and facilitators in delivering care in LTRC. The General Manager also supported the study by writing a letter of support to the Canadian Frailty Network, which funded two years of this project.

3.2.3. Recruitment

To gain access to the care aides, recruitment was conducted by the Director of Care and the Recreation Therapy Manager on the complex care floor of Green Lodge. A schedule was created to guide the interviews. The Director of Care and Recreation Therapy Manager would "double book" a care aide so that she was covered to leave the floor for up to two hours to participate in an interview. Care aides who were booked to participate in the interview sample represented all shifts (day, evening, night); all experience levels (from new graduates with less than 6 months' experience to very seasoned care aides with more than three decades of experience); all several ethnic identities (First Nations, Caucasian, Hispanic, and Filipino); and all levels of employment (casual, part-time, full-time). To purposely seek out diversity along the identified variables of age, gender, ethnicity, and experience level, the researcher worked closely with the Director of Care and Recreation Therapy Manager, who knew the population of care aides extensively and could ensure that there was an equal representation of care aides in each of these variables to participate in the interviews. All care aides were invited to participate in an interview by both the Director of Care and the Recreation Therapy Manager. When each care aide was booked for an interview, she was informed, both in a group setting and privately, that she could decline at anytime and with no negative repercussions. Since the manager asked each care aide to participate in the interviews, there were power dynamics at play, which will be addressed in further detail in the study limitations section of this thesis.

To ensure that participants clearly understood the purpose and expectations of this study, meetings with the facility's leadership team and care teams were held to strategize how best to make the researcher's presence and purpose of this study known to the community of care aides. To facilitate care aides' awareness and understanding of this study, the researcher attended meetings on all shifts and shift changes to briefly present the study and request participation from the care aides. The researcher also spent time on the complex care floor (approximately one hour each visit) before and after interviews and around the care aides' room, nurses' stations, and dining area to facilitate informal conversations with care aides to help familiarize them with the study and to express to them how much their time was valued and appreciated. It was from these informal meetings and time spent on the complex care floor that this study could obtain "buy-in" from keen care aides, who almost immediately saw the importance of this research. These "keeners" helped inform and motivate other care aides to participate in this study. From these meetings and unofficial exchanges, and with the supportive guidance and patience of the management team as well as other keen care aides, the researcher obtained buy-in from care aides to participate in this study.

Out of the care aides who were booked for interviews (31 in total out of 71 potential care aides), two openly declined to participate in a private interview. The first care aide declined to participate because she said she wanted to stay with her residents (she was working short staffed and did not want to take the time away from delivering care). The second care aide declined to participate in an interview because she was concerned that the interview was being conducted by a "corporate spy" who was hired by management. Her concern, as was explained by both the Recreation Therapy Manager and another care aide, was that information gained from the interview with her was going to be used to reprimand other care aides who were not meeting corporate standards. This second instance is discussed in greater detail later in this chapter as well as in Chapter 6 and in the final chapter on the reflexive analysis of the research experience (Chapter 8: Discussion and Conclusion).

3.2.4. Sampling

This study's sampling process was designed to obtain rich data on the experiences and perceptions of care aides in one complex care floor in a LTRC facility. In qualitative research, there are several criteria that guide subsequent decisions related to sampling, including the experience of the researcher, the methodology chosen, and the complexity of the phenomenon under study, although the main factor that determines the sample is the research question. Sample size is also to be decided based on the type of data that will be gathered. Purposeful sampling approach in qualitative research utilizes the following three considerations: (i) the decision as to whom to select as participants; (ii) the specific type of sampling strategy used; and (iii) the size of the sample to be studied (Creswell, 2013). The following section outlines how each of these three considerations was met and how purposeful sampling strategy was used in this study.

(i) Participants

This study employed a purposeful sampling strategy, meaning (as suggested above) that the participants were selected based on their experiences with the phenomenon in question (care aides' experiences in LTRC). At the beginning, the "big net approach" was used (Fetterman, 2010), which was facilitated by the researcher spending large amounts of time on site on the complex care floor in Green Lodge, mingling with everyone. Ethnographic researchers rely on their judgement regarding the selection of members of the subculture to answer the research questions. The researcher employed this approach during this study, as well as relied on the guidance of the management team (Creswell, 2013). Based on the rapport that was built with care aides during the informal interactions on the complex care floor, many individuals agreed to come and participate in private interviews with the researcher.

(ii) Sampling Strategy

The logic and power of purposeful sampling lies in selecting information-rich cases from which one can learn a great deal about issues of central importance to the purpose of the study (Patton, 2015). After the first few visits to Green Lodge, participants began to volunteer to participate or agreed to participate (when asked if they would be willing to volunteer) in interviews for the study. This study utilized maximum variation sampling because it was determined in advance that participants would be selected based on certain criteria (experience, shift work, and ethnicity). Gathering information-rich cases was achieved by ensuring that representation was of a broad selection of care aides who were employed by Green Lodge.

Although care aides were the sole population that participated in semi-structured interviews, there was variation within this group with respect to all levels of experience (6 months' to 35 years); age (26 to 55); gender (26 females, 5 males); and cultural ethnicity (Caucasian, Filipino, Hispanic, and First Nations). This ensured that a diverse sample was secured for this project. In addition, for participants who wished to have more than one interview, time was made available to conduct a second interview to continue the rich dialogue. In total, 2 out of 31 participants requested a second, follow-up interview.

(iii) Sample Size

In ethnography, it is common to sample from within single-culture sharing groups, with numerous interviews, artifacts, and observations collected until the workings of the cultural group are clear. A total of 31 care aides were interviewed for inclusion in this study out of a total of 71 care aides who were currently employed part- or full-time at Green Lodge.

3.3. Data Generation: Ethnographic Methods

In the research process, methods are considered to be the techniques or concrete procedures used to gather, generate, and analyze data related to the research questions (Crotty, 1998). The study used various qualitative methods to generate data, including semi-structured interviews, naturalistic observations, and reflexive journaling. In total, this project included the following data: 31 semi-structured interviews with care aides (70 hours recorded and transcribed verbatim); 170 hours of naturalistic observation (27 days and 3 nights in total); and 20’000 words of personal reflexive journaling. Alongside data generating methods a methodological journal was kept to extensively detail every decision in the research design, data collection, and analysis process (currently at 70’000 words). Trustworthiness will be discussed in detail in the final section of this chapter.

3.3.1. Semi-Structured Interviews

In the social constructivist paradigm, the questions in an interview or discussion with participants become broad and general so that the participants can construct the meaning of a situation, a meaning typically forged in discussions or interactions with other persons (Creswell, 2013). Although this is the case, it is important to note that within this study interviews began as very structured with both an interview guide (Chappell, 2007), and a unique interview method, the Multiple Sorting Technique (Sixsmith & Sixsmith, 1987). These two were later merged into one combined interview guide. With further exposure to and experience with the participants as well as guidance from the informal advisory group, in the end the researcher decided to use a simplified semi-structured interview guide and conduct the interviews in a more conversational style. The detailed reasons behind this decision are discussed in the section that follows.

Interview Guide

In the summer of 2014, five care aides were recruited for a pilot version of this study from a similar campus of care facility in a metro location in Western Canada that espoused a person-centred care (PCC) model. The data from the pilot interviews were not included in the final analysis of this project, but the pilot version was an invaluable exercise in facilitating a better understanding of the research context in interviewing care aides in LTRC. Inevitably the interview guide for the pilot version of this study was revised considerably due to the reflections that the interviews provided.

For the interviews at Green Lodge and based on her experiences in the pilot interviews, the researcher developed an interview guide that allowed her to have open, natural, and conversational discussions with the care aides (Appendix A: Interview Guide).

The study interviews began with the researcher saying: “This is your interview. I want to know your experiences of being a care aide.” The following seven pre-defined questions were included in the interview guide:

1. Tell me why you became an RCA.
2. Tell me about a recent shift.
3. Describe to me a resident that you particularly enjoy caring for.
4. It is human nature to not enjoy everyone that you care for. This example does not have to be from this facility but can you please think back and describe to me a resident that you find particularly unenjoyable to care for.
5. Tell me about a particular co-worker that you thoroughly enjoy working with.
6. It is human nature to not enjoy everyone that you care for. This example does not have to be from this facility but can you please think back and describe to me a co-worker that you find particularly difficult to work with.
7. Tell me about a situation when you were not able to deliver the care that you wanted to deliver.

Other than the conversational interview guide approved by Simon Fraser University’s ethics board, the questions that were used during the semi-structured interviews evolved during the course of the conversations and interviews as they would normally arise, with each interview informing the ones that followed. Thus, the interviews and the subsequent interview questions proved to be iterative in nature. As such, the questions emerged as the data unfolded and the interviews built on these.

Interview Process

Interviews were conducted on site at Green Lodge. The average interview length was 68 minutes (with a range between 37 minutes and 153 minutes). Most of the interviews took place in a private room in the independent living floor of the facility. The General Manager at Green Lodge booked both coffee and snacks for most of the interviews. When conducting interviews during the evening and night shifts, the interviews often took place in either the care aides’ room (which also doubled as the storage closet) or the activities room, both of which were located on the complex care floor. Since there were fewer care aides employed on night and evening shifts, the interviews often took place in locations closer to where care was delivered because it was easier for the care aides to maintain contact with their "partners" and fellow care aides should anything come up where their assistance would be needed. Although being interviewed in close proximity to their fellow staff members and residents may have infringed on the care aides' ability to focus, due to the reality that many of the interviews were conducted while they were already working "short," it was necessary to make some sacrifices to the interview processes to ensure that all care aides who wanted to participate could do so.

The ability of an interviewer to establish rapport is often considered to be one of the most important skills for effective interviewing (Bell, Fahmy, & Gordon, 2016). Prior to beginning the interview, I engaged in informal conversation with each participant to build rapport. Before asking the care aide any questions, I introduced myself and explained the study as well as what was to be expected during the interview, including confidentiality and the fact that the interview would be recorded and later transcribed. I would then ask if there were any questions I could answer prior to beginning the interview. Before the recorder was turned on, every participant was asked three brief questions:

1. If they were coming on or off a shift (to assess their energy level);
2. If they were working short-staffed (to assess their stress level and urgency to make the interview quick so they could get back to their residents) and;
3. If they had ever participated in research before (to assess their comfort in participating in research).

In all 31 interviews, only one care aide said that she had participated in research before. Once these questions were answered, I would read the consent form out loud with the participant (Appendix B: Study Information and Consent Form). I took extra effort to make explicit (often by circling or underlining) where my supervisor's name was on the consent form and described him as "my boss." Then I explained to each participant that my supervisor was the person to contact if he or she felt I did anything unprofessional or unethical. The rational for doing this was to show the care aides my own vulnerability and to make apparent that I had my own form of "job insecurity" and that the participants had some "power" over me and the success of this study. I did all I could to begin the conversation/interview on as equal a plane as possible with the care aides. Finally, I would sign the consent form and ask for the participant's signature. I also asked each participant to please keep the consent form on his or her person, or and to not leave it lying around Green Lodge for others to pick up because it had important information in it. Once the consent form was signed, and with the participant's permission, I turned the tape recorder on. Almost every care aide was visibly nervous at the site of the tape recorder, yet no care aide asked that the interview not be tape recorded, even though every participant was made aware that she or he had the choice not have to have the interview recorded. By giving participants this choice, it was another way that rapport and trust was able to be established with the care aides.

During the data collection process, I did all I could to ensure the participants that no one, especially the management, would ever have access to the recordings. I told the participants that "the reason I record these interviews is because, in my experience, members of the healthcare team can give a lot of valuable information in a very limited amount of time, and I do not want to miss anything important that they say." I started the recording by saying something directly to myself in the recorder to break the ice and show the participant that I was not a threat. Something as simple as *"Hello, Laura, I am with PG [XXX], it is a lovely day today, I hope you graduate soon*," was a lighthearted effort to make the care aides smile. No one declined to have the interview recorded; however, as is common when conducting interviews, many participants spoke at length once the recorder was turned off. Alongside recording each interview, I also wrote down notes that were not only a way to help me remember important key topics, but also a way to help the care aides to see that I was engaged in what they were sharing. Each participant was told that these notes were just for me but that he or she was welcome to ask to see the notes at any point during or after the interview. I attempted to be as transparent as possible with the participants. On several occasions, I would draw a diagram to represent something that a care aide had described and then show it to the participant and ask if it accurately reflected what he or she had in mind. To allow the care aides to have space to release their anxieties about being interviewed or the emotions that the interview brought up, I always had extra paper and different colored pens on the table so that they could doodle or make their own notes throughout the interview. I wrote field notes after each interview to record how the interview went, key events that may have affected the interview, and first thoughts about the issues covered in the interview.

I took care with my appearance, knowing from previous experiences in LTRC that showing up to interview care aides in a blouse and blazer is not an appropriate way to reduce the perceived power differential between myself and the participants. Also, from my knowledge of Old Town, the only people who wear suits are predominantly members of the Town Council and those who work at the bank. With this awareness, I dressed casually for the interviews. Both the way I dressed and the way I spoke were important for building rapport with the participants (Gubrium & Holstein, 2001). I could never completely blend in with the care aides because they were always wearing scrubs and name tags and I was not. Regarding the way I spoke, I learned not to use the "research language" that I had become comfortable with and instead changed my language to match the participants, as reflected, for example, in the following field note:

> She told me about resident-resident aggression. I need to remember not to use language like "resident-to-resident" aggression when I speak to care aides or people who are not academics because they will not understand what I am saying—it is too technical language. They know what it means but they use a different term and I should use that when speaking with them. [Field Notes 06.13.16]

I also worked to build a rapport and familiarity quickly by mirroring the care aides' behaviors and attitudes, which often may have been easier for me because of my knowledge of the town and surrounding area. When they participants swore, I sometimes swore. If they didn't like the union, I did not like the union. I made my vulnerability apparent by saying things like *"I am a student, you are the experts,"* or "*I don't know how to do what you do … I don't know about shifts, caring techniques, etc.*" I did what I could to make it obvious that I was conducting this study to help care aides and that I was by no means a threat to their job security.

Challenges

There were several challenges encountered during the interview process that were not adequately accounted for during the planning phases of this study. These challenges include issues of: (i) trust and power; (ii) differences in beliefs of the researcher and the care aide; and (iii) traumatic incidences.

(i) Trust and Power

The concept of power in LTRC holds many issues for conducting empirical research due to the sensitive nature of the setting. In the interview context, the researcher holds almost all the power and the participants are often seen as comparatively powerless (Kelson, 2013). Because of this power dynamic, during the interview process, I worked to ensure that I did all I could to maintain a physically neutral position. This included sitting side-by-side with the participant in a comfortable area. I also often walked up to the complex care floor to meet with the participants, often waiting for them while they finished their tasks and then walking down with them and taking the elevator together to the ground floor where most of the interviews were conducted, all the while speaking casually about the weather and general events occurring at Green Lodge and in Old Town in an attempt to gently build rapport with the participants prior to entering the interview setting.

I was aware of the issues of power and resistance between staff members linearly as well as hierarchically (Baumbusch, 2008). Historically, relations among these groups are structured within a strict hierarchical system, which formally and informally shapes the way that care is organized (Jervis, 2002). As such, I was aware of this linear and hierarchical organization of power and took precautions to ensure that the research findings remained confidential from other staff members as well as from management. These precautions included not speaking to the members of the management team about the interviews or about the participants. This sometimes created an awkward conversation because the members of the management team were very interested and invested in the study and often wanted to know how it was coming along. When I stayed in Old Town, I often had meals with the management team, who were friendly and would regularly ask how the study was going. I would attempt to quickly and politely end or divert the conversation while continuing to build relationships with the management team. During the interview process of the study, I could be seen as a “multi-dimensional counterfeit insider”—that is, with the management team, I easily became one of them, but when I was with the care aides, I could switch to become a member of their team, albeit not as easily and definitely never a full member, just an affiliate care aide in acceptable standing.

From other members of the care staff to management to the corporation, care aides report not trusting anyone in LTRC. They often trust other care aides, but there is still a large percentage who do not trust anyone in the LTRC setting, including other care aides. Despite all of this, they perceived they had to answer to everyone for the care they deliver. Because of this lack of trust, building rapport with participants was often difficult. Care aides reported not trusting participating in the interview because they believed the researcher was hired by management. I wrote the following field note after conducting an interview with a participant. Two other staff members had already requested that she go down to speak with me (she was on the complex care floor and I had an interview room two floors down, on the independent living floor). When reading this excerpt, please keep in mind that all of this took place after the Director of Care, Recreation Therapy Manager, and I, the researcher, told the participant why the study was being conducted.

> Initially when it came to 1pm I had to go upstairs to go get her on the 3rd floor. She was concerned with talking with me—the first comment she made when we got in the room was “did management bug this room.” Her body language was cold and uncomfortable, she continually played with her hair elastic on her wrist the entire interview. It was a very difficult interview and I did not feel like I was able to get good data on it OTHER than the fact that she did not want to participate in research. Her lack of interest and my inability to build rapport made me nervous and tired and it was very hard to get data from her. She yawned in the interview and was generally unengaged. Funny thing though, as soon as I turned off the recorder she wanted to show me photos of her daughter on her phone…and at the end of the interview I went up to bring her the pen she left down with me and she gave me a big smile and thanked me. Definitely not the warmest care aide that I have interviewed—not the coldest, just not interested in participating in research. [Field Notes 05.26.16]

During several interviews, I could tell the participants were visibly uncomfortable speaking with me:

> My interview with [Betty] went well. At first I could tell that she was very standoffish and concerned with the tape recorder, but then I could see that she got comfortable with me. I showed her the recorder, showed her how to turn it off when the time came that she wanted to say something private. I told her that we would not use any identifiers. I did everything I could to make her feel comfortable.
>
> NOTE: when RCA are nervous, be calmer. Give them more space to talk. Be more relaxed.
>
> After the interview was done, I thanked her and told her that that was such a terrific interview for me . . . She said “that was great” and that she was so nervous at the beginning, but over time she even forgot that there was even a tape recorder. In the end, after she left the interview room, she turned around and gave me a big hug. She thanked me for all that I was doing. [Field notes 11.06.15]

It was apparent that many care aides, including Betty, had never participated in research before. In fact, during nearly every interview I asked *"have you ever participated in a research interview before?,"* and only one participant out of 31 replied *"yes."* With this knowledge, I made every effort to ensure that I did nothing that would further the participants' discomfort. I explained the *"I take notes to help me remember what's on there [the tape recorder], so anytime you want to grab my notes and you're like, 'What are you writing?,' please do it."* If I saw participants look at my notes, I would show them what I was writing and make sure they understood it was merely to remember the important points they were sharing with me.

Beyond this being a new and often intimidating experience to be interviewed, participants also explained that in order for them to take part, they often had to make sacrifices as a team. For instance, Helen, a 44-year-old Caucasian care aide with 8 years of experience, mentioned that in order to participate in the interview she had to share her workload with the other care aides: *"On the wing I'm working on today, there are 22 residents. And, so now, the other two care aides I've left there are responsible for all 22 while I'm off the floor."*

My presence at Green Lodge was clearly a point of concern for some of the care staff members. At one point, there was a rumor circulating the floor of the facility that I was a *"corporate spy hired by the company"* that owned Green Lodge to assess the state of the care aides. Realizing that a rumor monger may affect the evaluation of this study, I did what I could to dispense with this rumor. I spoke with staff members on every shift and explained (again) who I was and why I was there. I also did my best to use my sense of humor and show empathy. I brought the staff members cookies from the local bakery in Old Town with hand drawn cards that read *"Thank you for speaking to me,"* and on the inside *"I am not a corporate spy."* I thought it was quite clever. I laughed and the staff laughed too. [Field Notes 06.08.16]

In my interactions with the staff and future participants, it became clear that it was only a select few care aides who felt that I was actually a corporate spy, and I was aware that this could have "peer influence" on interviews. Despite this, the suspicion that was held regarding my role as a researcher at Green Lodge was evidence of the lack of power that care aides felt in their role.

Prior to learning about the rumor that I was a corporate spy, I would inform the participants at the beginning of the interview that I was not in healthcare and had never worked in healthcare, other than as a researcher. As such, I was in no position to tell them how to do their job nor assess if they or their colleagues were doing their job well. I simply wanted to know about their experience as a care aide in LTRC. As seen in the following excerpt from my interview with Helen, it sometimes came in handy not knowing the jargon that the care aides used because it allowed me to show my openness to learn from the participants:

> **Helen:** Well, no. Well, like, if the care aide has done their training and, like, the students have done their training at a facility where there is overhead lifts . . . right, and then they come here and it's all manual, so MSIP, musculoskeletal injury prevention—
>
> **Researcher:** Remember, I'm not in healthcare, I don't know MSI—I'm a researcher.
>
> **Helen:** MSIP.
>
> **Researcher:** So, musculoskeletal . . .
>
> **Helen:** Injury prevention.

It was also common during the interviews for care aides to ask me to ask the management or the overarching corporation to buy them *"ceiling lifts."* It was apparent that they thought I had the power to influence and lobby the corporation and management to acquire these lifts for them.

Building rapport was not always difficult, however. The longer the study went on and the more time I spent on the complex care floor at Green Lodge, the more care aides were open to participating in an interview and the easier it was to build rapport, as reflected in the following field note excerpt: *"Very easy to build rapport with this man. He had a brand-new tattoo on his arm and we built rapport right away."* As time went on, the care aides began to get comfortable and tell their fellow care aides that I was kind and harmless and that they should also participate in an interview. For example, the following field note is from my interview with Judith:

> She was a nice woman in her late thirties with dark brown hair. We went into the storage room (?) or some type of staff room together for me to interview her. [Later I found out this is the care aides' staff room/storage closet.] I showed her the consent form and we went through it together. She told me that she would be a lot more cautious to be interviewed by me if Shelley hadn't said that she has been talking to me for years (I corrected her that it was barely even one year, but still . . . I made a joke about Shelley exaggerating and we both laughed. I think that built more rapport.) [Field Notes 06.11.16]

(ii) Differences in Beliefs

There were several instances during interviews when participants said things that were directly against my personal beliefs, and I had to make a conscious effort not to appear judgemental or disapproving. For example, many times participants would make ageist, sexist, and racist comments, and I did my best to continue with the conversation, as shown in the following field note:

> One of the last questions I asked Stephanie was if she had ever seen racism in LTRC. She said that when she went to school at CTI (some college in Surrey) she "didn't even know what country she was in." But she said she has never seen any racism. She also said that "Filipinos are lucky to be here…" so that makes me think there is racism that just isn't out in the open. [Field Notes 02.16.16]

(iii) Trauma

Sometimes participants would get emotional during our conversations (see the field note below) due to the sensitive nature of the topics discussed and because the care aides often reported that the interview was the first time they felt *"listened to."*

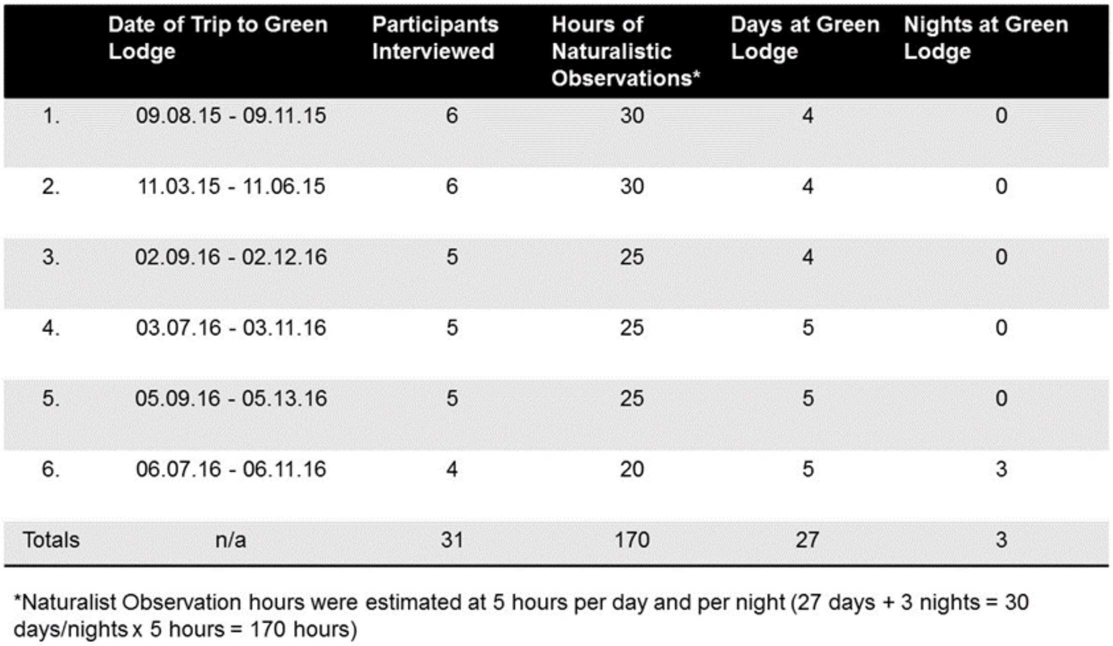
> Many times (perhaps four or five) Betty brought up the fact that she had to "quit" her [previous job in LTRC] because it was too horrible. She said that her brother had to come and rescue her and it took her six weeks just to get back on her feet. I asked her, what happened? She told me that she may cry and that she "has never talked about this to anyone." [Field Notes 02.16.16]

Another issue that came up was when participants would use the interview as an opportunity to discuss trauma they had witnessed during their occupation as a care aide. Based on my previous experience working on a crisis line (I-800-Suicide) and as a hospice volunteer as well as my past experiences in LTRC, I felt I was equipped to listen to the care aides' stories. I was able to direct the participants to their Director of Care and local mental health support networks.

3.3.2. Naturalistic Observations

Naturalistic observations are used to examine social and cultural practices *"where the group works"* (Savin-Baden, 2013). The researcher initially had a structured observation schedule approved by the university ethics board. Over time, the observation schedule proved to be more of a barrier than a facilitator to interacting with care aides, so instead of physically bringing the observation schedule along during visits to Green Lodge, it was memorized and mentally referenced as observations were conducted. Observations were informally used to reveal how other members of the care staff team, management, maintenance, and residents all interacted with the care aides. Alongside the interviews, observations were conducted over a 10-month period at Green Lodge (September 8th 2015 to June 22nd 2016). Observations were also used to establish how care aides interacted with each other. Often, and due to the nature of the occupation of delivering care to residents, there were many long durations of time where I was left waiting for a care aide to come and be interviewed. These times were also utilized as observation periods. I would sit in an open room overlooking the complex care floor of Green Lodge or in the dinning room on the same floor and observe the care aides. With permission from "keen" care aides, I would also shadow participants with whom I had built a strong rapport. I would walk with them as they conducted their rounds and often they were kind enough to introduce me to other care aides as well as the residents they were caring for. Sometimes I would assist the care aides in completing small tasks such as bringing coffee or water to residents. Mostly I stood in the background and observed what the care aides were doing and who they were interacting with, without interrupting them. Through these naturalistic observations, I was able to take extensive field notes on my experiences at Green Lodge, which allowed for ongoing reflections and observations to be recorded. Field notes were recorded either directly after observations or in the evening after data was collected and ranged in length from 2 pages (500 words) to 6 pages (2'000 words).

Due to the rural location of the facility, each trip resulted in, on average, 4.5 days onsite at Green Lodge. Each trip to Old Town and Green Lodge was a 5-hour journey, one way: 2 hours by bus, 2 hours by ferry boat, and 1 hour by car (150 kilometers of travel in total). This commute, although time consuming, allowed for a great portion of reflexive journaling to be accomplished. Also, because of the length of the commute, when I was onsite at Green Lodge, I felt completely immersed in the facility, with limited distractions from my everyday life.



	Date of Trip to Green Lodge	Participants Interviewed	Hours of Naturalistic Observations*	Days at Green Lodge	Nights at Green Lodge
1.	09.08.15 - 09.11.15	6	30	4	0
2.	11.03.15 - 11.06.15	6	30	4	0
3.	02.09.16 - 02.12.16	5	25	4	0
4.	03.07.16 - 03.11.16	5	25	5	0
5.	05.09.16 - 05.13.16	5	25	5	0
6.	06.07.16 - 06.11.16	4	20	5	3
Totals	n/a	31	170	27	3

*Naturalist Observation hours were estimated at 5 hours per day and per night (27 days + 3 nights = 30 days/nights x 5 hours = 170 hours)

Table 3.1. Data collection methods utilized during each trip to Green Lodge

3.3.3. Reflexive Journaling

At a fundamental level, reflection is the turning back or illumination of something. Reflection as a mental process involves consideration and meditation or turning thoughts back upon themselves. For qualitative researchers, reflection involves thinking and meditation about processes and products associated with a study (Savin-Badin, 2013). Reflexivity is a process of critical analysis of past events that helps researchers to consider their position and influence during the study. Reflexivity also helps researchers to know how they have constructed and even sometimes imposed meanings on the research process. Gillespie and Sinclair (2000) argued that one of the criteria for “good” qualitative research is reflexivity. They wrote that there is the need for work to be self-reflexive and detached in examining the disclosure of the researcher's own commitments, relevant experiences, and social position. As described by Pinn (2004), it is impossible to take oneself out of the research, but reflexive processes allow for an understanding on how oneself and one's history, as well as the systemic setting within society and culture, affect the study at hand. Research is not conducted within a vacuum and there were many influencing factors that affected the creation of the research questions and interview design.

In consideration of Dupuis' (1999) assertion that the qualitative researcher is necessarily intertwined with the study participants in the production of data or knowledge, reflexive journaling throughout the research process provided a means by which the researcher could reflect on the preliminary outcomes as well as the personal experience of and response to those processes. In this case, reflexive journaling allowed the researcher to document everyday observations of occurrences and norms at Green Lodge, as well as thoughts and impressions of these observed events and interactions, which allowed for the process of critical analysis (September 8th 2015 to June 22nd 2016). The following expert speaks to how I used the reflexive process of journaling to critically review what I was doing as well as how to make the critical analysis stronger and why:

> I am noticing that every RCA has experience in other LTRC facilities, either in the past or presently working in these facilities. I do not want to parse out the experiences between The Gardens and the other facilities because I am looking at the "holistic experience of the RCA," NOT at the "RCA Experience at The Gardens." It just so happens I am interviewing them all at The Gardens but I want to get a "big picture" idea of their experiences—not a snippet of their current experience. In such, I will be coding the experiences that occurred in other LTRC facilities in with The Garden's experiences. I will not be separating the two. [Reflexive Journal 12.13.16]

My reflexive journaling, observational notes, interview notes, and field notes all served as reflexive tools throughout the entire research process.

Often consequences of qualitative researchers are emotional responses to the data obtained. Dupuis (1999) described this as an integral part of scientific inquiry. In this project, some of the events, experiences, and observations shared by the care aides had an emotional effect on the researcher. Reflexive journaling was not only a method to organize thoughts and gather data, but also an important component of the study that allowed the researcher to get close to the data without causing emotional distress. As such, reflexive journaling was both a method for data generation as well as an important component of analysis and interpretation of the data.

3.4. Data Analysis

In qualitative research, data has primacy and the process of data analysis is not a linear, binary process but instead an on-going iterative, time-consuming endeavor that requires patience, grit, and reflexivity (Savin-Baden, 2013). Data analysis and interpretation tend to occur at the beginning of a study and are inductive processes. Researchers tend to move from the specific to the general or from the data to the description of theory. Such movement is inductive rather than deductive and demonstrates the primacy of the data. Patton (2015) explained that over the course of fieldwork ideas emerge regarding the directions for analysis, that patterns take shape and possible themes come to light. As such, hypotheses emerge that inevitably inform subsequent fieldwork. The beginning of analysis comes when ideas for making sense of the data first emerge. Finding patterns is but one result of the analysis; finding uncertainties, ambiguities, and vagaries is another outcome of qualitative analysis. Coffey and Atkinson (1996) described the process of qualitative data analysis as follows:

> “A cyclical process and a reflexive activity; the analytic process should be comprehensive and systematic, but not rigid; data are segmented and divided into meaningful units, but connection to the whole is maintained; and data are organized according to a system derived from the data themselves. Analysis is, on the whole, an inductive, data-led activity.” (Coffey & Atkinson, 1996, p.10)

Analysis Process

For the analysis process, I relied heavily on the guidance of Michael Quinn Patton’s work (2002, 2013, & 2015). During the analysis process, I immersed myself in the data and Nvivo11 and lived with my transcriptions, code book, and methodological journal. For guidance, I consulted with my supervisory committee as well as Patton (2013, 2015) and Creswell (2013). I had copies of the research questions pasted throughout my apartment and wrote in my methodological journal daily, recording my thoughts, ideas, and frustrations throughout the analytical process. My most common form of self-care during this process was running. It was common for me to stop mid-run and record a voice memo on my phone if an idea or reflection came to mind. I did my best to own my interpretation and make the difference between the description and interpretation distinct. For my interpretation, I worked to stretch my mind to go beyond the mere description of the data. Following Patton (2013), I attached significance to what I found and attempted to make sense of my findings by offering explanations, drawing conclusions, and extrapolating, considering, and creating meaning. As Patton (2013) described, I worked to impose order on an otherwise unruly but clearly patterned, hierarchical, and organized world. I consciously worked to stay away from the trap of making linear causal analysis and attempted instead to interpret the data using a holistic perspective that describes the interdependence and interrelatedness of complex phenomena. I worked to ensure that I included the following in conducting my analysis (Patton, 2013, p. 480):

1. Confirmed what we already know about LTRC that is supported by data;
2. Disabuse use of misconception; and
3. Illuminate some of the many important things that “we” did not “know but that I believe are important to know to improve the situation in LTRC”

Patton (2015) described concepts that have played a central preordained role in guiding fieldwork as *sensitizing concept*s. These concepts are a way of organizing and reporting data. The data from this study had initially been organized as sensitizing concepts. In comparison to sensitizing concepts, *indigenous typologies* are classification systems that are made up of categories that divide some aspect of the world along a continuum (Patton, 2015). Typologies stand on “ideal types” or “illustrative endpoints” rather than a complete and discrete set of categories. The differences seen involve a mere degree of interpretation rather than concrete, absolute distinctions. To be able to reveal indigenous typologies within a mountain of data, Patton (2002, 2015) asserted that the researcher must conduct an analysis of both the differences and similarities among participants in a setting to break up the complexity of reality into digestible and distinguishable parts. He also stated that the language of a group of people, (in the case of this study the care aides) highlights what is important to them because they have given something a name to set it apart. As with all groups, organizations, and cultures, care aides have developed their own language system to emphasize distinctions that are apparently important to them. The task is to find out how care aides create their perceived world of experience in LTRC from the way they talk about it.

This process-focused inductive analysis began by creating an inventory of the key phrases, terms, and practices that are special to the care aides at Green Lodge, or the *indigenous concepts* and *practices* of the care aides. Before beginning field work, I had already developed a list of *sensitizing concepts* that I had perceived as being important to be aware of and to study. *Sensitizing concepts* are used to orient fieldwork and refer to categories that the analysist brings to the data. These concepts originate in the already established research literature and theory pertaining to the study. Sensitizing concepts allow for the research to have a general sense of reference as well as a direction point from which the research can look (Patton, 2013). These concepts can be thought of as lighthouses that, when one is in the dark and lonely parts of analysis, are sources of comfort and encouragement; they reveal that others have come this way before and that the findings have been replicated in the past. Applying these concepts involves exploring how they were created, used, and understood by the care aides at Green Lodge.

After I developed an inventory of indigenous concepts, typologies, and themes, the next task for indication was to look for patterns, themes, and categories that enabled me to create a typology to further clarify findings (Patton, 2013). A series of patterns that emerged from the data was then further distilled into different themes. From these contrasting themes ideal types were created. This was the exciting part because with the development of these ideal types it became clear that the analysis was beginning to identify and form patterns that appeared explicitly to be unperceived by both the researcher and the participants at the beginning of this study. The first purpose of identifying typologies is to discretely distinguish the different aspects of the patterns that were observed in the data. I asked myself, *"What do the interactions with participants have in common? How can those commonalities be expressed?"* Throughout the qualitative inquiry, including analysis and reporting, questions of reflectivity and voice were asked to engage the data and extract findings. Self-awareness, even a certain degree of self-analysis, is also required in qualitative inquiry. Patton (2013) described three categories of questions to ask in order to triangulate reflexive inquiry:

> *Self-reflexivity:* What do I know and how do I know what I know? How has my background and my own perceptions affected the data I have collected from care aides and how has this shaped my analysis of this data? And perhaps the most interesting for my study: how do I perceive the care aides?
>
> *Reflexivity of those studied:* How do the care aides know what they know? What has shaped and continues to shape the worldview of the care aides?
>
> *Reflexivity about audience:* How do those who receive my findings make sense of what I have given them in my thesis and emerging issues? What perspectives do these individuals bring to the findings I offer? How does the audience who will be receiving my findings perceive me? How do the perceptions the audience has of me affect what I report and how I report it?

Triangulated reflexive inquiry provided a framework for sorting through issues during analysis and writing as well as provided an understanding of how these reflections informed the writing. With the guidance of the supervisory committee and qualitative researchers who were used as “academic muses,” my task first and foremost was to understand the experience of being a care aide in LTRC. The second task was to understand from their perspective what the strengths and deficiencies of LTRC settings are and how the delivery of care could be improved. I worked to allow the data to reveal the voices, perspectives, and experiences of those interviewed as well as the intricacies of their world (Patton, 2013). In the end, the findings and results of this thesis are a co-constructed account of the experiences of care aides in LTRC created by the researcher and the care aides who participated in this study.

3.5. Quality and Ethical Considerations

Trustworthiness

In any piece of qualitative research, it is necessary to establish the quality of the work done. To do this requires that the trustworthiness of the study be established. Shenton (2004) elaborated on Lincoln and Guba’s (1985) previously established framework for ensuring rigour in qualitative researcher: (i) credibility, (ii) transferability, (iii) dependability, and (iv) conformability. Each is discussed in the following sections.

(i) Credibility

In addressing credibility, Shenton (2004) stressed that investigators must attempt to demonstrate that a picture of the phenomenon under scrutiny is being presented. Therefore, for this project it was important to discuss how thoroughly the care aides' perspectives and experiences were included and described in the data. Credibility was established using the following: peer debriefing with members of the informal advisory group; triangulation of data sources (interviews, observations, reflexive journaling); and prolonged engagement with the study site.

Lincoln and Guba (1985) described *peer debriefing* as a mechanism by which to keep the researcher honest by helping to reduce researcher bias. Peer debriefing for this study was conducted through meetings with the researcher's supervisory committee as well as the advisory committee members. Peer debriefing was also conducted through informal conversations with other members of the Gerontology Research Centre at Simon Fraser University, including informal conversations with graduate students, post-doctorates, research associates, and faculty members. Peer debriefing helped the researcher to take a step back from the data and look through the eyes of her peers. Prolonged engagement is a strategy by which the researcher immerses him- or herself in the research setting for a sufficient amount of time to ensure an understanding of the context in which participants' stories originated (Lincoln & Guba, 1985). For this study, prolonged engagement with the study site included multiple trips to the LTRC facility, with six of those visits specifically for data collection.

(ii) Transferability

To allow for transferability, Shenton (2004) described how researchers must provide sufficient detail of the fieldwork context for a reader to be able to decide whether the prevailing environment is like another situation he or she is familiar with and whether the findings can justifiably be applied to the other setting. *Transferability* was confirmed using *thick description*, which Lincoln and Guba (1985) defined as a way of achieving a type of validity. Thick description of a phenomenon in adequate detail allows one to begin to evaluate the extent to which the conclusions drawn are transferable to other people, times, settings, and situations (Lincoln & Guba, 1985). In contrast to a “thin description,” which is a superficial account of an event or phenomenon, a thick description is a detailed account of field experiences whereby the researcher makes explicit the patterns of cultural and social relationships and places them in context. Thick description is not merely about reporting detail, but instead demands interpretation that goes beyond meaning and motivations, and so there are a number of ways in which researchers may accomplish this description (Savin-Baden, 2013a).

This thick description of the researcher’s entire study design and process provided an index of transferability as well as the database that made transferability judgements possible. To address credibility, qualitative researchers attempt to establish that a picture of the phenomenon under scrutiny is being presented (Shenton, 2004). To facilitate transferability, the researcher must provide sufficient detail of the fieldwork context (in the case of this study both Old Town and Green Lodge) for a reader to be able to decide whether the prevailing environment is like another situation he or she is familiar with and whether the findings can justifiably be applied to the other similar settings (i.e., other LTRC facilities in Canada).

(iii) Dependability

Shento (2004) asserted that for researchers to sufficiently meet the criterion of dependability in qualitative work, they should strive to enable a future investigator to repeat the study. *Dependability* is showing that the findings are consistent and can be repeated (Lincoln & Guba, 1985). This often takes the form of an audit trail, or the “decision trail,” left by a researcher that allows others to trace the methods used (Patton, 2013). The researchers audit trail took the form of her methodological journal, which includes explicit and organized reports of the research so that the reader can evaluate and replicate the analytic logic that was employed.

(iv) Confirmability

Finally, to achieve confirmability, Shenton (2004) argued that researchers must take steps to demonstrate that findings emerged from the data and not from their own predispositions. Confirmability was established through the triangulation of different perspectives during data collection and analysis and represented a critical method of establishing the trustworthiness of the research (Streubert, Speziale & Carpenter, 2003). The researcher is not an objective outsider to the research; therefore, it is acknowledged that his or her preconceptions are part and parcel of research. Reflexivity is used to analyze what influence preconceptions have on the research. Madison (2012) stated that ethnographic researchers need to make explicit their positionality and acknowledge their own power, privileges, and biases, just as they denounce the power structures that surround those they study. Reflexive journaling, observation notes, interview notes, and field notes all served as reflexive tools throughout the research process. The researcher also worked to make herself explicit within the project, including her motivations, biases, and interests.

3.6. Limitations

The following section will address this study's limitations. First, the findings are context specific in that this thesis focused on a single floor within one campus of care facility operating within a unique geographical area and situated within a health authority that is unique to Vancouver Island. To address this limitation, there is a need to understand the perspectives and experiences of care aides across a larger range of urban and rural settings to facilitate a broader comprehension of the perceived barriers and facilitators in their delivery of care to residents in LTRC. Second, only care aides from one LTRC facility were used as participants due to the exploratory nature of this research. Also, although the sample included a wide range of ages, experience levels, and ethnicities, as well as both genders, the ethnicities were limited to only those represented at Green Lodge. This presents a significant limitation to the reproducibility and generalizability of the findings, because the reality is that most care aides in LTRC in Canada are migrant female workers and visible minorities. The generalizability is only able to make claims about the experiences of the care aides who participated in this study. Data for this research was collected at a single point in time for each participant, so it is not possible to determine the stability of the responses.

It must also be stated that in a small-town setting such as Old Town and Green Lodge the anonymity of participants can be confirmed, but not the confidentiality of participants. I did my best to ensure anonymity (i.e., coding participants as numbers and not by name from their initial interactions with me; never using identifying characteristics in my field notes). But there is only so much that can be done with a small population within an even smaller population. As such, anonymity was confirmed, but not confidentiality.

These qualitative findings rely upon a relatively small sample size, and to establish commonality there is a need to capture further insights from care aides across a broader range of settings and LTRC facilities.

Also, it could not be determined whether there were differences in the experiences, opinions, and behaviors of the people who agreed to participate and those who declined to take part.

Finally, regardless of my intent to be as objective as possible in the interviews and with the study observations and analyses, the lens through which I viewed the data undoubtedly influenced what I saw and how I interpreted it. My personal experiences and preconceived ideas or beliefs may have caused me to put more focus on some elements of the data set and less on others.

Despite these limitations, this study adds to the body of knowledge that suggests that improving the quality of care for residents in LTRC is directly related to improving the quality of the work life of the care aides. Consistent with the published literature, findings from this study indicate that this latter reflection is an area in need of significant attention.

Chapter 4. Findings Part I: Care Aides Training and Entry into Long-Term Residential Care

These results cover 10 months of fieldwork (September 2015–June 2016) and are based on 70 hours of interviews with 31 care aides, 170 hours of observations, and 20’000 words of reflexive journaling. The story that this data tells allows for a glimpse into the perceived collective history of care aides employed in long-term residential care (LTRC). The findings of this study offer valuable insights into the events and decisions that shape the journeys made to become a care aide, including their micro and macro experiences and interactions within this setting. The overall aim of this study is to understand the experiences of care aides in LTRC as well as their perceived barriers and facilitators in the delivery of care to residents. The results of this thesis are separated into three parts, which organically formed from the general sequence of the interviews I had with the participants. This current chapter, Findings Part I, describes who the participants are surrounding their role as care aides, why they initially chose this career, and their caregiving experience in the past. Part II goes deeper into what the care aides’ roles and relationships are with other members of the LTRC community. Finally, Part III offers a substantial review of some of the challenges that care aides experience and how these are perceived barriers to their delivery of care.

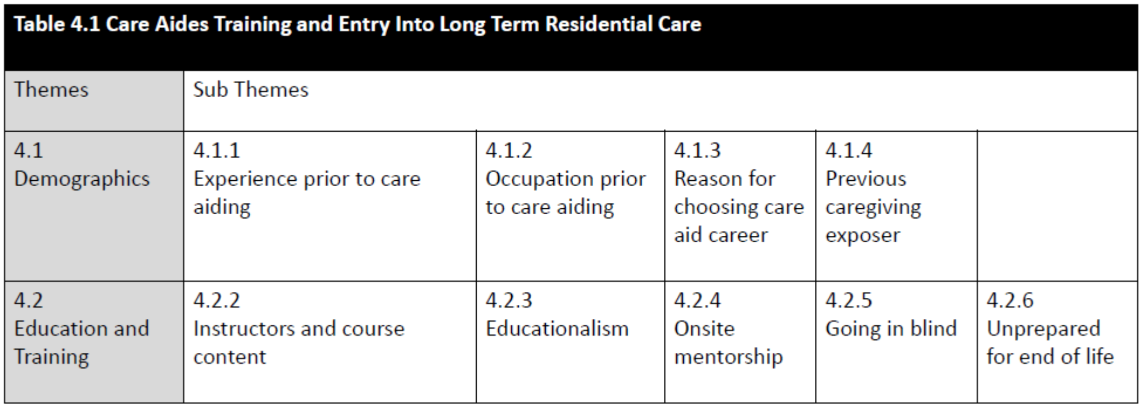


Table 4.1 Care Aides Training and Entry Into Long Term Residential Care

Themes	Sub Themes				
4.1 Demographics	4.1.1 Experience prior to care aiding	4.1.2 Occupation prior to care aiding	4.1.3 Reason for choosing care aid career	4.1.4 Previous caregiving exposer	
4.2 Education and Training	4.2.2 Instructors and course content	4.2.3 Educationalism	4.2.4 Onsite mentorship	4.2.5 Going in blind	4.2.6 Unprepared for end of life

Table 4.1. The main themes presented and discussed in this chapter. The themes relate to the care aides’ training and initial experiences upon entry into long-term residential care.

This first part of the findings shares what careers the participants had prior to working as a care aide, the reasons they chose this occupation, and their previous exposure to this occupation, both formally and informally. The chapter also presents in general the participants' experiences with older adults as well as within the LTRC setting prior to finding employment in this sector. Finally, this chapter concludes with a discussion of the participants' experiences of being trained as a care aide and their initial experiences upon entering LTRC as a care aide.

4.1. Demographics

This section begins by introducing the demographics of the participants in this study, how long they have been employed in this sector and how many LTRC facilities they have worked for. Table 4.2 shows the demographic information of the care aides who were interviewed. As previously stated, participants were purposefully selected to represent all available ages, ethnicities, experience levels, employment levels, and shifts. The participants' ages ranged from 26 years to 55 years, with the mean age being 42.2 years. This large age range reflects that information was collected on the perspectives and experiences of being a care aide in the early years of life while providing a comparison to the experiences of being a care aide in the later years of life. Age appeared as an important variable for participants' experiences. Participants often shared different experiences, concerns, and life issues. For example, younger participants spoke of taking time off to have children, and older participants discussed raising children or helping with grandchildren, as well as the accumulated injuries related to an increased amount of time spent working as a care aide (such as chronic pain). Out of the 31 participants, most identified as Caucasian (n = 26), which is an accurate representation of the population of Old Town. It must be emphasized that this is not an accurate representation of care aides working in LTRC. As discussed in Chapter 2, most care aides employed in LTRC in North America are migrant female workers. In this study, two participants identified as Filipino, one as First Nation, one as Hispanic, and one as Chinese. Again, most participants were female (n = 26), while the other five identified as male. As seen in the 2016 Canadian Census, this gender divide is a nearly accurate representation of care aides in LTRC, where women outnumber men four to one. No participants in this study identified as transgender.

Table 4.2 shows that there was great variability among the experience levels of participants regarding their employment as a care aide in LTRC. Five participants had less than 2 years of experience, eight participants had between 2 years and 5 years, and ten participants had between 6 years and 10 years of experience. Impressively, over a quarter of this sample (n = 8) had over a decade of experience working as a care aide in LTRC. Among all of the participants, there was on average 8.5 years of experience working as a care aide in LTRC. Most of the care aides interviewed in this study had previous experience working in LTRC settings other than Green Lodge. The range was between one and eight different LTRC facilities, while on average participants reported having had experience working as a care aide in two to three different LTRC facilities. Many care aides reported being employed specifically at Green Lodge for a range of 2 months to 12 years, with an average length of time of 5.4 years.

Information from Care Aides Interviewed (n = 31)	Average	Range	Breakdown
Age	42.2 years	26 years–55 years	< 30 years 31–40 years 40–50 years 50+ years
Gender	n/a	n/a	26 female 5 male
Ethnicity	n/a	n/a	26 Caucasian 2 Filipino 1 First Nation 1 Hispanic 1 Chinese
Years working as care aide	9.2 years	0–30 years	< 2 years: n = 5 (16%) 2–5 years: n = 8 (26%) 6-10 years: n = 10 (32%)

Information from Care Aides Interviewed (n = 31)	Average	Range	Breakdown
			> 10 years: n = 8 (26%)
Years working in long-term residential care	8.5 years	0–30 years	< 2 years: n = 5 2–5 years: n = 6 6–10 years: n = 10 > 10 years: n = 8
Years working at Green Lodge	5.4 years	0–12 years	n/a
Number of LTRC facilities worked at	2.4 facilities	1–8 facilities	1–2 facilities: n = 20 3–5 facilities: n = 5 6–8 facilities: n = 2 Unknown: 4

Table 4.2. Demographic information from participants.

4.1.1. Experience

The first question participants were asked during the interviews was simply, *"For how long have you been working as a care aide?"* The answer to this question dictated the tentative direction of the subsequent questions. If the participant had less than or approximately 5 years of experience as a care aide, the subsequent questions asked in sequence would often pertain to their education experiences and their initial experiences working as a care aide. If the participant had been employed as a care aide for more than 5 years, questions about education and their initial entry into LTRC were often neglected and more time was spent discussing their experiences in LTRC.

4.1.2. Occupation Prior to Working as a Care Aide

This section presents the participants reported previous work and life experience as it relates to their current employment in LTRC, as well as their vocational experiences prior to being employed as care aides in LTRC. As stated earlier in this chapter, the mean age of the care aides who were interviewed was 42 years, and the average length of time that the care aides reported working in LTRC was 8.5 years. Participants came to LTRC with a wealth of experience and knowledge form previous employment and life experiences. Often these experiences were from completely different sectors than healthcare.

Out of the 31 participants, 23 shared what their occupation was prior to working as a care aide. Five participants shared that they had previously been employed in a field related to health and well-being (an esthetician, a phlebotomy lab assistant, a nanny, an acupressurist, and a group home worker). Three participants were stay-at-home mothers prior to working as a care aide. Only three care aides shared their experiences working as a community care aide prior to entering LTRC. The following is what Donna, a 32-year-old Caucasian woman with 7 years of experience in LTRC, had to say about the comparison between the two roles:

> I did community as well. And I like fast-paced. The community was such a little bit too slow for me. And it wasn't—like it isn't long-term care. Like long-term care is more personal. And then there's—I don't know. On the community, it's just a lot of housework, this kind of . . . I feel like a maid. You know. . . . So it wasn't for me. **(Donna)**

Another three participants were employed in the trades, including two heavy equipment operators and a landscaper. Brad, a 45-year-old man and member of a First Nation with 8 years of experience working at Green Lodge, came to work as a care aide after *"building highways."* He stated the following during our interview:

> **Researcher:** Why did you switch? Just because there's no more work? What happened?
>
> **Brad:** Yes, no more work. I just finished up Courtenay. Building highways up in Courtenay and I was on E.I. My sister happened to phone me up, there's extra funding. . . . Yes, if I wanted to take this course. I said, "Sure, I'd give it a try." Haven't looked back.

Although the participants described their entry into working as a care aide as to some extent forced by circumstances beyond their control, most felt that, ultimately, the move had been a good one for them. The largest group of participants (14) shared that they had previously held occupations in the customer service and retail sectors prior to working as a care aide.

4.1.3. Reasons for Choosing to Work as a Care Aide

Hearing participants describe how they became aware of this line -of -work was always an interesting conversation. Through asking participants *"how did you first learn about this occupation?"* it opened the discussion to describe where they were in their life at the time of learning about this career, and who initially brought it to their attention as a viable option for employment for themselves.

Although every participants' story was unique to their own lived experiences, there did appear to be common reasons that characterized the path these individuals traveled to become a care aide. These reasons included: (i) a forced necessity, (ii) a personal desire, and (iii) a stepping stone. These reasons are by no means mutually exclusive or exhaustive. They are the most salient patterns coming from the participants regarding why they chose a career working as a care aide.

A Forced Necessity

Karen, a 47-year-old Caucasian woman who had worked at Green Lodge for 9 years as a care aide, described a forced route of entry into healthcare:

> I was a border operator and a forklift operator. [I switched over to residential care] because [the] lumber industry and forest industry . . . was slowly twiddling off and there is always work in healthcare. [When I chose this course] I was thinking of job placement after I graduated. And I know that healthcare—people are living longer . . . there was a lot more facilities being built. So I just knew that this would be job stability for me. That was my main reason for taking it. Coming from the lumber industry, I needed something that was going to keep me working until I retired. **(Karen)**

This change in occupation from working with machines in a predominantly isolated and male-dominated environment to working with vulnerable people in a female-dominated setting was stark. Karen described her experience of changing from the trades to healthcare, where she *"had no experience,"* as *"scary."* Nevertheless she did it and has been working as a care aide in LTRC for 10 years now. Later she stated that *"when my* *mom was young, when she was a nursing student and because she got pregnant with me, she didn't graduate. So, I'm the first, I guess."* Karen is speaking to the fact that she is the first person in her family to graduate with a post-secondary certificate. The participants commonly expressed that *"being the first"* was a reason for choosing a career as a care aide. There is a sense of pride and accomplishment in gaining an education to be a care aide. It is interesting that often within the care aide's social circle, or nuclear family, he or she may be viewed as a trailblazer as the first person to receive a college diploma. Despite this, the care aides' macro social circle, or the greater society, does not always view their academic achievements and roles within healthcare in such a positive light.

A Personal Desire

Out of the 29 participants who discussed their reason for choosing to be a care aide, 21 shared that they had a desire to care for people and were interested in what a career as a care aide was. It was a common point of discussion among participants that one of the overarching reasons they chose this career was to *"help people."* For example, one participant reported that he *"always wanted to do a job where I'm helping people . . . and [my] original idea was to go into firefighting—cause [I] did eight and a half years as a volunteer—but for whatever reasons, it didn't happen. And [working as a care aide] seemed like a good idea."* The consensus among the participants who spoke about being in the category of "needing to find a job" was that there were "always jobs in healthcare." Ten participants spoke about their financial struggles and how the role of a care aide appeared to lend itself to financial security and job stability. Out of those ten participants, three came from the trades. In comparison to care aides who came to this occupation out of forced necessity, the next largest portion of participants seemed to be those who expressed a life-long calling to care for others. These care aides felt they were *"born to do this."* They described how they *"have always wanted to do a job where [they are] helping people."* A calling is described as a strong urge toward a way of life or career; a vocation. These participants discussed their calling to deliver care to others. As was the case of Jane, a 55-year-old Caucasian women with 18 years of experience as a care aide in LTRC:

> I just loved to be more hands on with people and to fulfill their needs and fulfill my needs as well, like, it's like a—I felt a desire to be—I'm not the type of person that would sit in an office. I can't do that. I need to be more moving about. . . . I just

> knew that this was going to be it. So it was like a—I had a feeling that that's what I wanted to do. Intuition, yes. **(Jane)**

There were different ways that participants expressed finding this calling. Some came to the job out of necessity and then found that they loved it, as was the case with Brad in the excerpt above. The same is true for Mellissa, a 32-year-old Caucasian care aide who had been working at Green Lodge for 8 years. When I first asked her why she became a care aide, she said: "I didn't graduate high school. So I guess I got tired of working for $9, $10 an hour." But then later, when I built more rapport with Mellissa, I asked her again why she became a care aide, and she said:

> I've always been a people person. I get along great and just have a great connection with—I can get along with like anybody. Any—I don't know. It was just for me. I felt like it was—for me, and it was also good education for someone who didn't have graduation or anything. I just was looking in the paper one day, and it was like there. I'm like, "Huh. How tough is that?" Like I was looking for work and this ad popped up for Discovery. "Become . . . " you know "in six months." I'm like, "Yes, great. Well, I'll give it a try."

She later said, *"I feel I am here for a purpose, to help people and take care of them where nobody else can. It was something I felt I was supposed to do."* This sense of a calling was reported by some participants to have manifested at an early age and grown with time until they found themselves in the care aide role. As was the case with Sandra, a 55-year-old Caucasian care aide with 27 years of experience in LTRC:

> From a very young age, I've always been interested in the nursing field. . . . I would go, during school, if somebody would get hurt, like I'm thinking back to grade two, even someone . . . I would take the minute at the club room and play the nurse, bandage and then have them sit like in a waiting room. [I would] end up getting in trouble from the teacher because we were in there playing doctor and not in the class. Yes, so at a very early age, I have always wanted to do something in this field. . . . It was nursing to begin with and then probably in my early 20s, I watched both grandparents of mine—grandmother and grandfather—pass away of cancer within nine months of each other. And I watched my parents, my mom and her sisters, take care of them because around here, there wasn't a lot [of resources to help with the caring]. **(Sandra)**

Participants also discussed how they were drawn to this job through experiences and affection toward older adult members of their families, such as grandparents. Often, participants reported having been raised by their grandparents, and how this bond was the main driving force that propelled them toward a career in caring for older adults. One participant described how she *“really wanted to work in a nursing home . . . [and] to take care of elderly people.”* When asked why she had this motivation to care for older adults, she spoke to how her *“my grandparents raised me as a child and now I am really orientated with elderly people.”* She continued by saying that *“when I first moved to Old Town [from another province], all of my friends were 65 and older.”* In Canada, it is not a common experience to be raised by grandparents. Care aides often spoke about having had this unique upbringing or spending a significant amount of their childhood being parented by grandparents. This experience was often reported as *“eye-opening”* to the realities of life as an older adult. Participants spoke to how their relationship with their grandparents gave them a form of empathy that allowed them to better understand the population of older adult residents they would eventually go on to care for. For example, one participant reported that *“I spent a lot of time growing up with my grandparents because my mom was a single mom. So I was always with my grandparents and always kind of involved in their community.”* When asked if she thought that experience made her more empathetic toward the older adult population, without hesitation she answered *“Yes, yes . . . And [I’m] more comfortable with them, absolutely.”*

Participants also shared stories of other people telling them to become a care aide, as was the case with Judith, a 38-year-old woman with 2 years of experience at Green Lodge:

> I’ve always kind of looked after people since I was 10. I started looking after my special-needs brother when my mom and dad went out. So we had a heart monitor and a tummy tube. And I had to get special permission to take the babysitter’s course with the 12 year olds. So, yes, it’s kind of what I’ve always done. And my grandma, probably about 15 years ago, she would come up to my parents on the weekends. The nurse happened to be there. And I’d help toilet her. And she just grabbed my arm and said, “Why aren’t you working in a hospital?” I said, “I’m on it, grandma. I’m on it.” **(Judith)**

Participants reported wanting to understand healthcare and care delivery, so that with this knowledge they would be able to deliver care to their loved ones when need be. Ruth, a 40-year-old Caucasian care aide with 8 years of experience at Green Lodge, described having learned about caring for someone following a stroke after her father had one:

> Actually, my dad had a stroke, so I thought I better learn a little bit more about it. And, yes, I took care of what I [could] do for him to help him and everybody else. **(Ruth)**

As previously mentioned, participants often spoke to wanting to care for others from an early age and discovering a lasting aspiration to help people, but they never mentioned the specific role of a care aide. Two speculations as to why this was the case are that perhaps participants were unaware of this occupation, or if they were aware it was not an attractive or feasible choice of occupation. In lieu of this, care aides often reported a desire instead to become a nurse, either a Licenced Practical Nurse (LPN; RPN in Eastern Canada) or a Registered Nurse (RN), but the following constraints had thus far prevented this from occurring: (i) the financial, tuition costs were too great; (ii) the time needed to obtain the necessary education was an unachievable commitment; and (iii) the entry-level requirements to pursue the education needed were not attained or seen to be unattainable. Due to these limitations, employment as a care aide was seen as not to be a viable option. As one care aide with three years of experience described, she *"I always wanted to be a nurse, but my marks just weren't there."* She continued by saying that *"the care aide works for me."*

In some instances, care aides reported choosing this career because it was seen as a "low-risk" investment regarding education commitments and there would be a high probability of job stability and security. As one participant described, "*I wanted to be an RN . . . and then my mom said, 'No, you got to go and take a course that will get you out in the market fast and get a good job.' I was like, 'okay.'"* This participant discussed receiving family pressure to follow this line of vocation to ensure she would quickly be employed in a financially secure position. This perspective makes apparent the lack of economic stability that care aides have and, considering this, how important it is to obtain a "good" career. It also shows how care aides are often younger women who receive guidance from members of their family in relation to their occupation choices. It may also be that this participant lacked power within her own family, such that she did not have complete autonomy over her career choice.

A Stepping Stone

Although most participants reported feeling joy from their role, some were adamant that they could be doing something else and that soon they would be re-tooling and going back to school to become a nurse (either LPN or RN). These participants explained how they perceived their role as a care aide as merely a temporary position and that the destination of their career path instead was in nursing. As one participant explained, *"I am going to go back to school and continue my education to do the practical nursing [LPN course]."* When asked why she would rather switch to that healthcare occupation, she stated that *"it is only because of the physicality of [the care aide] job, . . . that's part of why I think people burn out. It's very physical and emotional . . . I want to be able to touch my own toes when I'm older."* She further stated that she realized she was fortunate to have the opportunity to go back to school in the future, that she was *"lucky enough that I would like to continue with education and that I am smart enough to do it*".

Some participants expressed that because they were experienced in the care aide role, they no longer had a desire to become a nurse and were satisfied in their current occupation. One participant with 12 years of experience stated how *"I really wanted to be a nurse when I was younger, but I did not do it then because I was so young and just wasn't settled enough."* She described how although *"I think I could do it now, I don't want to."* When asked why she no longer wanted to be a nurse, she described how *"I don't want to be bent over, charting all the time and [how the nurses at Green Lodge] always seem to be so busy doing stuff."* She continued by explaining how she enjoys *"hands-on care work"* and how happy she is working as a care aide. Here it can be seen that this participant, although she originally wanted to be a nurse, decided to stay in the role of care aide because of her exposure to the occupation and through self-awareness and self-reflection. The role of care aide best suited her needs.

4.1.4. Previous Caregiving Exposure

Regardless of their preceding employment experiences, participants reported a variety of different opportunities in which they were exposed to the act of caregiving prior to entering healthcare. Of the participants who spoke of their previous exposure to caregiving, 18 cared for a family member. For instance, one participant spoke about how she “grew up with her special-needs brother.” Nine participants mentioned they were parents during their interview. Several participants shared stories of their previous exposure to caregiving. For example, one participant reported that when she was back home in Asia, she saw her *“aunties and uncles who were dying of cancer and my grandma and my grandpa went to my house. They stayed in my room. And [the family] took care of them there.”* She discussed how the *“hospital [was] then in our house, that’s where they went and died. That’s where they wanted to die, and [be cared for].”* Another participant, a 33-year-old Filipino woman who had been working a Green Lodge for one year, shared how there are no LTRC facilities where she is from (note her English is broken):

> I worked in Taiwan. I was a caregiver. And then I came here. . . I came here as a nanny for two and a half months. And then when I got my permanent residency, I worked in a hotel and in a fast food. -… Yes, some, like I took to -- I think the passion for taking care [of people] but I think that’s why I’m confident to get the care aide course. . . . I grew up in the provinces and we don’t have a nursing home in there. It’s like far from the city. It’s like mountains [laughs] . . . Yes, it’s far. So, it’s far from the city so we don’t have facility. We take care of our grandmothers. They live with us. We don’t take them to the care facilities**. (Clare)**

Several participants linked experiences of providing care to family members as having helped to make them more aware and empathetic toward the care aide occupation. Others linked a sense of empathy to their own experiences receiving care. For example, one participant shared a story about how she was initially exposed to this occupation through a traumatic experience in her young adulthood:

> I was in my early 20s, I got pneumonia and I was put in a hospital and almost died. . . . It infected my heart and lungs. I was in a coma for six weeks…When I woke up, I couldn’t walk or anything. I was so deteriorated and pretty much close to death. But I had to be in the hospital for months to learn to walk and use my legs and stuff again. . . . And just kind of experienced watching . . . [care aides] who were my age have to change my diapers and—because I couldn’t move out of bed. It was—yes, it was kind of—I don’t know how it . . . I [feel] I got here for a purpose, to help people and take care of them where nobody else can. [Being a care aide] is something I felt I was supposed to do. **(Melissa)**

This event, and the patience the care aides showed her, led Melissa to realize that she had found her calling and her purpose—to care for those who can no longer care for themselves.

Participants spoke of wanting to be prepared to care for their family if anything should happen in the future. This desire may have come from previous negative experiences with bad care, as was the case with Sharon, a 39-year-old Caucasian care aide:

> **Researcher:** So, are you able to tell me why you became an RCA?
>
> **Sharon:** I've always been in a customer service type industry, a lot of times coming from a place of no. And I'm more of a place of yes. I like to be positive and happy and make a difference. So, being in insurance, I was saying no a lot and not able to help enough people. But I have a genuine passion for people's well-being. And I just thought, "I need to find something I'm passionate about." And it all just kind of worked together that way.
>
> **Researcher:** Did you know anyone who was a care aide?
>
> **Sharon:** I didn't know a care aide, but I [saw] my grandfather go through cancer where he had a type of colostomy and a certain—you know, he needed care. And our family was uneducated about that type of care. So, my grandma became the care aide. And there—his last year of life was pretty hard on everybody. . . . Mm-hmm, I never healed through seeing the way he—it all went down for him. So, I just knew that as my parents aged that I wanted to have more background knowledge for anything that would come up. . . . My dad has cancer, my mom had blood pressure issues.
>
> **Researcher:** What did your mom think when you said you were going to go back and become a care aide?
>
> **Sharon:** She was worried about the dirty side of it, like the excrement and the urine. My mom can't wrap her head around the reason why I would ever want to do that. . . . And then I explained, "Well, when I was a baby, what would you do with me? And didn't you know that I deserved that?" And so, I just explained, "They deserve the same thing." So, she gets it. Of course, she wishes I was a rocket scientist, but that didn't happen so, . . . but she supports whatever I do because she knows I'm going to do it anyway.

It is interesting that even though Sharon openly stated that she became a care aide because she felt it was more aligned with who she is as a "yes" person, she also wanted to be able to care for her parents when they are older. Sharon openly expressed how she never healed from seeing her grandfather's experience with cancer and how it was for her family, and still her mother expressed concern about the "dirty side" of the role of a care aide.

Along the same line of how empathy grew from their previous exposure to caregiving, participants also mentioned a notion of "giving back" to humanity. They discussed an innate feeling that compelled them to be a care aide. Often the premise of this drive was described by participants as a need to show their love, respect, and support for the older adult population. Jane described how she sees the older generation as not being valued as well as her own experiences of feeling neglectful and, it is because of this that that she decided to become a care aide

> I became a care aide because of my grandmother. My grandmother and I lived together in Asia when I was younger. We would fight a lot. I now assume that she had Alzheimer's disease . . . but we didn't know back then. We would fight and I would call her crazy. When my family immigrated here, we left grandma in Asia. . . . It was kind of a wake-up call about how I'm treating the elderly and it made me feel really bad for what I did. So, I read more into it, I tried to do a little volunteer work, kind of like a payback for my grandmother—show respect and stuff for the elderly. And then I fell in love with [being a care aide in LTRC]. **(Jane)**

Another participant, Sharon, reported that she valued caring for the older generation because she believes it is because of their struggles that subsequent generations may thrive. In her view, because older adults lived through wars and times of intense scarcity and other hardships, the generations that followed, including her own, could live without adversities of that magnitude.

> I'm big on believing that we wouldn't be where we are in our society without the seniors paving the way—through war, through family, through rationing. . . . And you see that in their behaviors. The rationing and stuff like—there's people that will hoard because they never had anything. And you see that behavior here. You see the effects that the war had on people. . . . And it just makes me hold them that much more dear. I think a lot of people think of this more as a job. And I think of this more as a passion. . . . It just depends on your mindset. **(Sharon)**

Again, it is this notion of "giving back" to the older adult generations for what they have done in their lives to help the younger generations that is a recurring motivation for participants who chose this career.

Another question asked of the participants was *"Did you know of anyone who worked as a care aide before you became a care aide?"* There were a substantial number of participants who reported having known of at least one person who had been a care aide (n = 13) but the rest did not report not knowing anyone who was in this line of work.

Often participants reported that it was these friends who would suggest that they too become care aides. Interestingly, Cynthia, a 33-year-old Filipino participant with one-year experience at Green Lodge reported the following:

> I became a care aide because I wanted to see what's in this profession. . . . Like 90% of my good, close friends are [care aides] and all of them told me that, "Oh, no. Don't take this course." . . . I said, "Well, I want to see what you guys are doing. Why are you guys all telling me not to do it?" . . . Maybe because the nature of the work, I don't know. Because they've been doing it for so long. . . . I don't know. Maybe they are not satisfied with what they're doing. **(Cynthia)**

Most participants reported that they were not aware of any friends or family members who were formally trained as care aides. In lieu of exposure to the formal care aide occupation in LTRC, participants more often told of informal exposure through experiences in their lives when they witnessed someone being a caregiver.

4.2. Education and Training

To gain a comprehensive understanding of the experiences of care aides in LTRC, it is imperative to also explore the preparation and guidance they received prior to entering the LTRC setting. As previously stated, becoming a care aide was often seen as an attractive career option for those who needed employment based on two key aspects: (i) job security that comes with caring for an aging population, and (ii) the limited amount of education that is required. This section reviews the participants' experiences regarding their education and training. Participants needed almost no prompting to discuss the joys and frustrations of their education. In general, they were in two camps: either they looked back at their education and training with frustration and disdain, or they thought it was a valuable and enjoyable experience. Their perspectives stemmed from the course subject matter, the quality of the instructors, and their fellow classmates.

4.2.1. Socioeconomic Status

Due to the increasing need for care aides, the Canadian government offers various subsidy programs to help alleviate the cost of tuition for students who come from low-income backgrounds. One participant described how the government and the schools *“gave 101% financially to support”* her education. She further stated that because of this financial assistance she *“studied from dawn to dusk”* to be a care aide, which highlights the determination this participant had to successfully graduate from the care aide program because of the financial supported she received to participate. As previously stated in Chapter 2, care aides generally do not come from affluent or financially stable situations and the finances needed to obtain further education may be hard to come by or may not be available.

Of the participants who spoke about their education and its cost, four told me how they paid: two out of pocket, one a loan, one partly government subsidized, and one fully government subsidized. Understandably, there seemed to be resentment among participants who paid their own way to go to school toward those who had their education covered by government subsidies. Seeing one care aide receive something for free that another may have had to save, sacrifice, and wait for may, understandably, have led to some animosity. This resentment was not represented by all participants in this study, but it was apparent from specific interviews. For example, Sharon, a 39-year-old Caucasian woman with one year of experience working at Green Lodge, shared her opinion on the matter:

> I think also with our industry growing as fast as it is . . . we’re pushing through a lot of people that might not necessarily be good at this job. And with the government, re-educating single moms, people on welfare . . . which is great—they put them through vocational colleges that cost me $11,000 to go to but the government paid. . . . But those people are single moms as well that are taking this because this is an education that’s been given to them. They might not be good at this or passionate or care, but they got to get off welfare. They got to get an education. And they got to get a job. So, you get people that are just here for the paycheck. **(Sharon)**

The indignation toward a care aide who received a “free education” while others paid steep tuition fees is thought to be an understandable outcome given the current circumstances of economic frailty among the lower socio-economic group from which most care aides come. Shelly, a 38-year-old Caucasian woman who has been working as a care aide for 3 years, explained her economic situation after getting her education and training:

> Yes, yes. It was a big student loan, but it was worth it. They just came to garnishing my wages. So, I'll be fighting that battle next. Still take 10 years to pay it off. I took one month off after my graduation and started working here. And they just slid in and are garnishing my wages at 30% off of every single pay check. . . . [I called them] and they bumped it down to 20% off of each pay check instead. I carpool to work, to and from work. I bus it into work and I carpool it home. I don't even drive a car. And they have just shoved me down. I mean, I have to prove, in my opinion, one more month of September that they have shoved me into poverty. I can’t even afford my basic standard of living. **(Shelly)**

It is important to note that questions regarding the cost of education were never explicitly asked during the interviews. The care aides repeatedly brought up the topic and wanted to share their experiences during the interview process. It was apparent that there was a high level of inequality and, more specifically, unequal support that care aides felt within their own cohort. Participants would often report during the interviews that initially part of the reason they were drawn to this occupation was because it paid more than minimum wage and it was accessible to those who had less than a high school education. Regardless of participants’ background experiences prior to working as a care aide and who paid for their education, once in the LTRC setting care aides receive largely the same wages and workloads (this is discussed in detail in the sections that follow). Despite this, it is apparent that there is a feeling of inequality among the participants.

The following section discusses the care aides’ experiences once they entered the educational setting. This section also describes more instances in which care aides feel inequalities among those in their cohort.

4.2.2. Instructors and Course Content: Where Is the Dementia Training?

Participants shared their perceptions of and experiences with their instructors. One issue that was repeatedly raised by some participants regarding their education was that they reported being incredibly discouraged and frustrated with the limited amount of useable knowledge they received in school and how their time was not used wisely during their education. As one participant with 5 years of experience described: *“My schooling was just 6 months. I barely learned a damn thing!”* Her frustration was evident from her tone, and even five years after taking the course she still harbored resentment about how her valuable time and money had been seemingly wasted during large portions of her education. She continued by saying *“I [couldn’t] tell you how many days I wasted in school—we spent an entire day getting a lecture on the dangers of gambling!”* Although learning about the dangers of gambling may be an important course requirement for some occupations, it is clear that this participant did not think it was a valuable use of her time, especially when it was necessary to learn so much information regarding the actual task at hand—training to become a care aide. Some participants had difficulty with and even felt bullied and patronized by their instructors, as is represented in the following quote:

> [The instructors] taught us about professionalism, but they don’t practice it. They are [practical nurses]. They don’t practice it. . . . I was absent one day [of school] and [the instructors] already [had] been talking about me [with the other students]. Those instructors, the first instructors, they were just talking about each other behind their backs or they [laugh]. [Instructors] need to be good examples—like when you're talking to your students, don’t treat them like they know nothing. You can’t do that. **(Cynthia)**

Although some participants reported that they felt that their instructors did not value their time, others saw them as a valued part of their training:

> When I was in class, I found that class was very new age, very touchy feely, it was very . . . We had a great teacher, she was wonderful, but she was very emotional. She was very involved in her job. She’d been a nurse for many years and she felt deeply about—she cared deeply about what she did. **(Jim)**

Although it can be noted that Jim’s quote is not entirely positive and a bit dismissive of the instructors’ experience.

4.2.3. Educationalism

Another issue that was common among participants was *educationalism,* which, in the context of this study, is defined as pre-judging another based on where and when the person received his or her education. Participants would often judge another care aides’ knowledge or ability to deliver care by where and when the person received his or her care aide education. Although there was this theme of educationalism, there did not seem to be a collective agreement among the care aides regarding which schools offered good training and which did not. As one male care aide with 13 years of experience reported:

> My class was 22 at the start; eight of us graduated on time . . . It depends where you go to school. . . . And then you got “lower end” ones [schools] . . . that pop out the [care aides] [Laughs] . . . [These schools] actually have little campuses in every little town around here. **. . .** They pump them out. They pump out the courses, they pump out the people, and everyone graduates. . . . And when I meet people, I go, “Oh, where’d you graduate?” And then we have some [registered nurses] we used to work for in those campuses as teachers and then they kind of told me, inside information, “Yes, my mandate was to graduate everybody.” Unfortunately, that’s what I was told. **(Ryan)**

From this quote, it is apparent that Ryan does not trust the quality of education that care aides received from some schools and that he perceives there is a mandate to increase the quantity of hireable care aides but not necessarily the quality of their education and training.

Since there are no nationally standardized educational requirements and no examination to measure care aide skills, there is a discrepancy regarding what care aides are taught and how they are trained. Some participants described one of the toughest aspects of their job in LTRC is being put in situations in which they are asked to work with someone who they deem is inadequately trained to deliver care. Participants would reiterate their apparent frustrations when working with care aides who had recently graduated and who were not trained properly for the tasks at hand in LTRC. As the saying goes, “you are only as strong as your weakest link,” and in the LTRC setting the same appears to be true. Participants discussed how inconsistencies in care aide education and training lead to errors and possibly injuries. The following quote highlights a conversation I had with a care aide with three years of experience regarding what it is like to work alongside care aides who have not received a comprehensive education:

> [Care aides come here] from different schoolings and it’s like, “Well, didn’t they teach you that properly? . . . We work side by side with them. So, they would do stuff and we would do stuff, and I’d be looking and—“Well, it’s not what we were taught. We were taught this way,” and, of course, I thought the way we got taught was better than how they got taught. **(Corrina)**

Corrina highlights the problems associated with different standards of training, noting that, of course, the way she was trained is better in performing the tasks at hand. Corrina speaks to the fact that there may be many ways to do one task, but there is a discrepancy between the care aides regarding what is the best way to perform a certain task. Even within these seemingly micro instances, it is apparent that care aides feel inequality among themselves regarding what are the best ways to complete the tasks at hand. Corrina also sheds light on another side of educationalism seen among the participants—that they perceived their education to be superior to others.

Another issue that was commonly reported by participants was the perceived discrepancy between staff who had many years of experience and those who had recently graduated. Participants discussed clashes between the care paradigms of those who have been *"in the system"* for years and those who were fresh with a new education. The care aides that were interviewed that were relatively new to the profession described difficulties in communicating with the more experienced care aides, as well as their frustrations upon entering LTRC and finding out that they were not able to fulfill their more progressive goals regarding care delivery due to the already established barriers:

> There's us that come out of school with these great, new ideas . . . And this is something they told us in school. When you get out there, you are going to be green and new. You're going to interact with people that are 20-, 10-, 15-year veterans. You're going to have to find your way to communicate and work together. So, a lot of times, we were just kind of more told to be quiet until we could find our place. So, I think that the new aged people that do try to come out and make change get kiboshed by the old age, the old attitude. **(Sharon)**

Sharon speaks to the frustration that care aides feel when they leave apparently progressive, enlightening educational settings in which they were exposed to care practices that they had been taught were the best care practices, only to find that there were too many systemic barriers standing in the way of being able to deliver care in the way they were taught.

The next section discusses further the reported perspectives of the participants regarding their workplace environment, their role within LTRC, and how they feel their work is viewed within society.

4.2.4. On-site Mentorship

Participants also shared that although school may not have prepared them for the reality of the job, the more experienced care aides were there to support them. Marie, a

27-year-old Caucasian care aide, graduated from her program two months prior to our interview and shared the following perspectives:

> **Marie:** I just became one [a care aide]. I just finished school in March (2016).
>
> **Researcher:** How did you find your schooling?
>
> **Marie:** It's 10 months. I don't think it prepares you very well. . . . They basically teach the basics for when you come here. So, total reality change, like it's very different than school for sure. . . . I haven't learned about lots in school, but it's just—oh, they didn't teach about all that when I went to school. So, when I came here, it was just like, shit. They didn't prepare me whatsoever. But, I mean, all the staff here helped me out. They're extremely, extremely helpful.

Marie places a lot of emphasis on the importance of mentorship from the other more experienced care aides at Green Lodge. Coreena, a 45-year-old Caucasian woman with three years of experience as a care aide, shared that she supplemented the gaps in her education with on-the-job learning from the more experienced women at work:

> **Coreena:** [At school], they didn't really touch on that other than you will get someone that has dementia and may not remember this or that but—we're never really taught about people being hit and all that kind of stuff. They don't really prepare you for that. At least I wasn't prepared for it.
>
> **Researcher:** How did you [learn to] communicate with someone with dementia?
>
> **Coreena:** You know, well, I just work with some of the girls that have been here for a while . . . and knew how to do it. . . . And I just work with them. They taught me.

Other, more experienced care aides spoke to the importance of being a mentor to new care aides, as was the case with Lila, a 51-year-old Caucasian woman with 15 years of experience working in LTRC:

> I mean, because it does take a bit to get going. You have to—like I'm a firm believer, "The more experienced, the better." And I think that's where the team work really comes in. I always let new staff know when I'm orientating, "This is my number. You can call me anytime." . . . And I will offer assistance always because it's hugely overwhelming. . . . I just think it's important that when you come in to a new facility and you're a new staff, you have somebody to lean on because it is very overwhelming. You're sent down the wing. You've got 12 people to get up. "I want you to do this," and you're thinking, "My, where do I start?" So, I will

> absolutely—I'll make them a cheat sheet. I'll write out who to get first. I do everything I can to help, everything. **(Lila)**

4.2.5. Going in Blind

Unfortunately, care aides reported feeling woefully underprepared for their actual role of caregiving in LTRC. The following section reviews the initial shock that participants reported experiencing when entering the LTRC setting and the stark realization that followed when it became apparent what their job required of them. There was agreement among the care aides who were interviewed that the reality of the role of care aides in LTRC was vastly different from what they had been prepared for during their education and training. Care aides discussed the often shocking reality check they faced when they entered LTRC for their first time, as with Jim, a 48-year-old Caucasian man with two years of experience at Green Lodge:

> When we went to practicum, we did our practicum with a nurse of 30 something years' experience. And she basically said, "Everything you've learned in class, throw it away [laughs] because this is the real world. This is how it works." **(Jim)**

Another participant with a decade of experience described the following:

> I remember my first practicum. It was a little scary. . . . I just didn't know what to expect. When you go to school, you'll learn about their skin integrity and skin tears and . . . I just remember changing one of the ladies and having to roll her, and just remembering, "Their skin definitely sags." . . . I had no idea. I mean, I never saw my grandma naked or anything, so I had no idea that that's kind of what happens. **(Karen)**

Karen brings to light the reality many care aides experience during their first encounter with older adult residents in LTRC. Many described the initial shock of putting what they learned in school into practice. An overarching theme reported by the care aides was the discrepancy between their experiences in the classroom and the tasks they needed to perform on the complex care floor. They reported facing a steep learning curve to bridge the gap between their school experiences and what the actual job entails. As one participant reported, not only did she not *"know anyone who had this job before,"* but she also *"went in kind of blind."* She remembered in school that she and her classmates only got up to working with maybe four or five residents, yet when she entered LTRC she immediately had 12 residents to work with. Another participant who had only been on the job for a year discussed how her *“first experience was kind of scary at the beginning because you don’t know what to expect.”* The following quote is from a participant who, with less than 6 months of experience, was among the most recent graduates who participated in this study:

> I haven't learned about lots in school, but it’s just—oh, they didn't teach about all that when I went to school. So, when I came here, it was just like, shit—they didn’t prepare me whatsoever. But, I mean, all the staff here helped me out. **(Marie)**

Marie, like several others, highlights the importance of mentorship from other more seasoned care aides, given the inadequate classroom preparation. Unfortunately, positive mentoring experiences were not always the norm. Equally as often participants reported working with seasoned staff who were either unwilling or unable to help new care aides get oriented with their new role. For example, Ryan, a care aide with 13 years of experience in LTRC, shared the following:

> [When] I first started here. I was like, “Okay. No problem. I can do it. I’m capable.” But I had some questions, of course. I was brand new to these residents. I didn’t know them inside and out yet, so I went to the other side of the hallway and I asked [another care aide], “What can you tell me about this person? How is that person?” “I don’t know. Find out yourself.” That’s the response I got . . . from the person who’s been around for a long, long time. . . . For the most part, a lot of new people would tell you they’re not welcomed. **(Ryan)**

It is apparent that Ryan entered the LTRC setting with a reasonable amount of confidence in his capacity to be a care aide, yet he was not prepared for the lack of team cohesion and support that he received from the other care aides. He also said that he does not believe things have changed for new care aides and that they are still unwelcome. The apparent stress, discomfort, and anxiety felt by participants when they initially entered LTRC was a source of discomfort for them as well as for their new co-workers, who now needed to “pick up the slack” to make up for the gaps in education and training among the new graduates. From the participants’ perspectives, properly trained and educated care aides are one half of what makes for successful newly graduated care aides; the other half is being supported by your co-workers. In comparison, untrained, inexperienced, and unsupported care aides can make delivering quality care to residents a difficult and dangerous job for everyone involved. Delivering good care is not just about training or mentoring, but also the individual care aide's personality, as reflected in the following perspective:

> You have to make sure that you're up for the job. You have to be up for the challenge because each day is different. . . . [I was told] "Oh, you're just going to get people up, dressed," you know. I never got told about people being . . . combative . . . not to the full force, until you actually get to the facility and it's like, "Oh, geez!" **(Corinna)**

Corinna makes an important point that will be highlighted in future sections: the individual must be up to the challenge of the tasks at hand. If a person is not able to meet the challenges of the daily changes and complex needs of residents, then he or she will not be a successful care aide. This is important to note because if care aides are being trained and educated for a job that is not actually the job they are going to be doing, they are being set up to fail. They are also not being given fair exposure to the realities of caregiving in LTRC, and thus they do not have an informed opportunity to personally reflect on whether they believe they would be a good care aide in LTRC. As previously stated in this chapter, most participants entered the LTRC setting with limited to no experience inside LTRC. The education they received was a disservice to the care aides, their future employers, and the residents by having shrouded the realities of their future role until they finally entered LTRC and were responsible for the residents' care and well-being.

4.2.6. Unprepared for End of Life

Dying and death are unavoidable in LTRC. As such, one might expect care aides to be adequately educated, trained, and supported to ensure that, first, the transition between life and death for a resident is as peaceful as possible, and, second, the care aides themselves are able to emotionally handle such events without suffering further emotional distress. Unfortunately, as found in nearly every care aide interview, participants did not feel that they were adequately supported to deal with this sensitive and imperative care-focused need. During care aides education and training, participants reported not being prepared to see *"real-life"* incidents of dying and death, as reflected in the following experience:

> I don't think [educators and management] think that we see stuff. . . . There seemed to be very little kind of real-life stuff involved [during education]. And, yes, when I actually started working as a care aide, it was like this culture shock of, like, "I did not know it was going to be like this. I didn't know any of this would happen." . . . Like, we just sort of expected everything we would deal with would be sort of easy and peaceful. Like, if someone died, we just find them dead. You know, like, there wasn't really any—you're going to sit there while someone claws at you in terror. **(Jane)**

Care aides seem instead to be trained to deal with an unrealistic version of end of life, which seems analogous to a care aide being taught how to change a baby's diaper during their education but not an adult's diaper. Although the two tasks may seem conceptually similar, there are great differences. This lack of preparation for what is a frequent occurrence in LTRC has the potential to negatively impact the dying process of the resident, the care delivery process of the care aide, and the grieving process, once the resident dies, of both the care aide and the family members, if they are present.

For various reasons, family members are often not present during end of life in LTRC. Whether this is due to the physical distance between the dying resident and his or her family, the non-existence of living family members, or neglect on the part of the family, a resident dying alone often weighs heavily on care aides. As with the following excerpt from Patricia, who has a decade of experience in various LTRC settings, care aides often reported vivid, often graphic, and heartbreaking memories of the first time they saw a resident die:

> **Patricia:** [When residents die], care aides go in and clean them, wipe them down, clean out their mouth, dress them, like put them in clean clothes because usually when they—when somebody passes away, they—go to the washroom or whatever, and, yes, then they call the funeral home and they come and get them.
>
> **Researcher:** What about for you guys as far as debriefing? Do you open a window or light a candle or turn all the lights off in the room or do anything?
>
> **Patricia:** No. Not that I've ever known, no. I know when I lost my resident, I went and I had to take a moment and I went and sat in the tub room for about 15 minutes just to—I was quite emotional because that was the first time, right? So, it was difficult.

Although some participants recounted predominantly negative experiences with end of life, they also reported believing that they knew support and help were available to them, albeit not formal or consistent support; there was someone the care aide could go to for help in dealing with his or her own grieving experience, as the following demonstrates:

> I know that our director of care, her door is open anytime. . . . And she is an amazing person that she actually had to—I can be honest . . . in December, we lost six people just from different times. . . . All of January, I couldn't answer a call that came in because I'd never faced death before like that. And I couldn't cope right away with all of those people that I had bonded with passing away. . . . So, I had a huge problem with that. And for a month, I couldn't come in until I sat down with my director of care. And she explained that you can make the end of their life the most beautiful by being there and giving them that care and the respect that they desire and just make it great. And then it doesn't have to be such a negative, horrible thing, as long as it ends the suffering. . . . So, it made me see that there is an upside. Even though it's tragic, it's there. **(Sharon)**

Care aides often have a unique, close relationship with the residents they care for, and with this exclusivity also comes isolation in their grieving experience. Sharon's experience illustrates the dramatic toll that death in LTRC takes on each care aide and how support is often found from other healthcare workers, in this case the director of care. Although Sharon stated that her director of care was available to speak with the staff when support was needed, it does raise the question of who is there to support the care aides when they return home from their shifts? As reported by one participant who had already been employed as a care aide in LTRC for 8 years: *"I'm just going to tell you this honestly. When I do my after-death care, I don't know how I do it, but I do what I'm required to do. And then afterwards, like when I get home, it's just like, 'Oh, my god. I can't believe I did that to a dead body.' Do you know what I mean? Like, it's hard.*" The disbelief that this care aide expressed speaks to the overwhelming situation that she was put in and still she completed the work, even in disbelief of what she was doing to a human body. Other participants reported that, despite feelings of sadness and shedding of tears, they had become accustomed to losing their residents, as in the case of Donna, who had 7 years of experience working as a care aide in LTRC:

> When somebody like that has just been with us for so long, it just is so hard. But at the same time, like, yes, you cry and you feel for the family and stuff like that. But I've kind of gotten to a point that I almost don't let it affect me. It's difficult when you work with them all the time, like, I didn't work with him all the time. Since I've been here. Yes. . . . So, it's not affecting me as bad as it's affecting her. But it's still sad, like I don't want to sound like a cold-hearted person or anything, but it's—like,

> he was a great person. . . . He was awesome. . . . He wasn’t my resident. But, well, they’re all our residents, but I just didn’t work with him on a daily basis. **(Donna)**

Interestingly, Donna sheds light on this notion of not letting the death of residents affect her. With experience and exposure to resident deaths, it is apparent that the care aides must create an emotional barrier between themselves and those they care for. This perspective was repeated by participants; that to protect their own well-being, they had to build distance and not let a resident death affect them so that they could continue to do their job. As in the case of Donna, she is concerned that she sounds “cold-hearted” and insists that she still cares for her residents. She had to make decisions, however, regarding which residents she would actively grieve for due to the constraints of her own emotional well-being and the tasks that must be accomplished for the other residents while she is on shift.

Alongside caring for residents, giving them palliative care, and caring for the deceased body, the care aides’ role at the end of life is still not done. Participants reported being put in positions where when a resident died, they then had to care for and attend to the emotional well-being of a grieving family member or close friend of the resident. Care aides are not trained to deliver grief counselling and not all care aides feel comfortable in this position. As Helen reported, she often felt distressed by and unprepared for the role of having to support the family of a resident, while also taking care of her own grief, completing the after-death tasks, and attending to the needs of other residents:

> The other thing too that’s hard as the care aide is where you work frontline for the family as well. So, you’re dealing with the grieving family. Okay, we have no training in how to do that. So, we’ve gone and done our after-death care and then usually always—sometimes either the family is there when the resident passes. So, we’re the frontline to support them for their grief. And we also develop really good relationships with family members as well, right? So, you’re very empathetic toward the family because they’ve just lost their loved one. So, you do your best to console them and everything. And then you kind of just keep going. That’s the hard part. [Laughs] **(Helen)**

This notion of *“just keep going”* is repeated often by care aides. In this revealing account, Helen also sheds light on how care aides seem to brace themselves to be able to support the family in their time of grief. It is when care aides leave the LTRC setting that they finally have their own time to grieve. But how do care aides express grief after a resident's death? Helen shared her experience of how she dealt with an increased number of resident deaths and how the situation had affected her emotionally:

> That is something that's been really hard, like maybe because we've had a lot of residents who passed away in the last three, four months. Like, I think 15 . . . out of 90 or 96. . . . Nothing is done here. Yes, I've actually just [laughs] been having a hard time with these many residents that have passed away. I've been having a hard time dealing with that lately because we just have to pretend like nothing even happened and keep going. Like, I will—it's happened several times where I start a shift, the resident dies right away. That's the first care I go do is after-death care. And then you just go to the next one. You put your fake smile on your face. And you pretend like nothing even happened. And you go, go, go, go, go, go, go. And I usually don't react to it until I get home in private where I can grieve. There's no grief counselling. There's no nothing. There is no memorial thing. Like, there's no nothing. **(Helen)**

Helen is a care aide with almost a decade of experience in LTRC. She is not a recent graduate who has never experienced resident deaths before. Each resident death weighs heavily on her. She makes note of the "fake smile" she must wear as she leaves one dead resident and moves on to care for a living one, and how she can hide her reactions and grief until after she gets home. This notion of "faking it" was recounted often by care aides regarding resident deaths. A final telling component of her experience is that after a decade of "faking it," she is frustrated and discouraged that there are no formal venues to grieve or get emotional support for her grief.

This chapter outlined the journey participants shared during their interviews, from becoming aware of an occupation as a care aide to gaining training, an education, and experience in the LTRC setting. Regarding the care aide role in end-of-life care, that LTRCs should do more to help them process grief by offering counseling, resources and a way to support their well-being and therefore the well-being of the residents they need to continue to deliver care to. It is clear that "faking it" is not a sustainable way to endure the moral distress involved in end-of-life situations in LTRC.

Next, Part II of the study findings examines the care aides' relationships with residents as well as with other members of the LTRC community.

Chapter 5. Findings Part II: The Role and Relationships of Care Aides in Long-Term Residential Care

This chapter reviews the relational aspects of the care aide experience inside LTRC by discussing the relationships negotiated within this setting, beginning with the participants' relationships with their residents and then moving on to their relationships with other care aides.

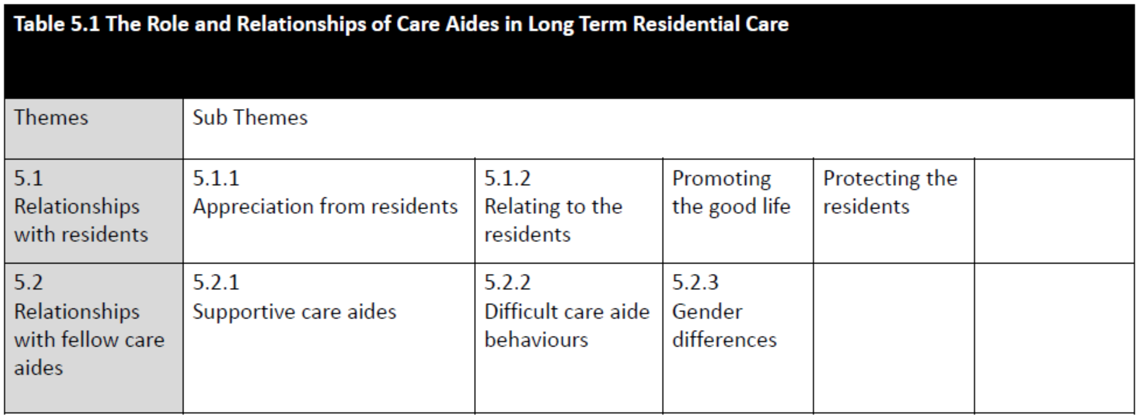


Table 5.1 The Role and Relationships of Care Aides in Long Term Residential Care

Themes	Sub Themes				
5.1 Relationships with residents	5.1.1 Appreciation from residents	5.1.2 Relating to the residents	Promoting the good life	Protecting the residents	
5.2 Relationships with fellow care aides	5.2.1 Supportive care aides	5.2.2 Difficult care aide behaviours	5.2.3 Gender differences		

Table 5.1. Main themes presented and discussed in this chapter. The themes relate to the care aides' relationships within long-term residential care.

Participants reported genuinely caring for their residents along with having a desire to do what is best to facilitate their well-being. During interviews, it was common for participants to state that *"the residents are the reason why I stay in this position."* Participants reported feeling joy from delivering good care and engaging positively with their residents. Despite this, participants reported being taught not to develop relationships with those they care for, a discussion of which begins the first section of this chapter. The section then presents the participants' feelings of appreciation from their residents, followed by a review of the types of relationships care aides reported having with their residents. Next is a discussion of the tasks that participants reported completing that extended beyond the required task-based care assignments. This chapter will conclude with a discussion of the perceived gender differences at play between the male and female care aides. Finally, the first section reviews participant suggestions regarding what should be done to help facilitate both their care delivery as well as the overall quality of life and well-being of their residents as well as perceived gender differences at play between the male and female care aides.

5.1. Relationships with Residents: “The Reason Why I Stay”

The following section presents a review of what participants revealed they were taught in school regarding how to approach relationships with those they care for in LTRC. Participants reported being taught what one care aide referred to as *“the dance,”* the point of which is to avoid developing relationships with those in their care:

> There’s lots of aspects that you learn [in school], and one of them is the dance, where they say, “Don’t get too involved in relationships with residents.” They call that “the dance.” There’s a whole book on it. And, yes, it’s like [Laughs] . . . And it’s just about getting involved with the residents, not getting too deeply involved, because it’s not your place to get too involved. The family is the ones that should be involved and when—if anything happens to the resident, then you don’t want to be emotionally dragged into it. **(Jim)**

Care aides, even prior to entering the LTRC setting, are taught to keep their emotional distance and to practice strong relationship boundaries with their residents. The reason for this, as Jim explained, is an attempt to protect the care aide from any moral or emotional distress that may take place when a resident’s health declines or the resident is involved in an unfortunate incident (examples of these incidents are discussed in Parts II–IV of this thesis). Care aides are taught to keep a protective barrier between themselves and the residents. The dance may be useful in settings where the residents’ family members play a large role and are actively engaged in the daily care nuances and decisions, but this is not the reality in LTRC. The underlying assumption here is that, to protect the care aides, the dance may help facilitate the relationships between family members and residents to allow care aides to maintain a professional distance and focus on task-based care. However, if a care aide chooses to abide by “the dance” and not form a relationship with residents, there is the possibility that the residents will be left alone on the proverbial dance floor, with no social support. This dance does not translate well within the realities of LTRC and the intimate relationship of caring for residents. Perhaps what this dance does instead is to facilitate the victim blaming that care aides receive when they report having a difficult time with a resident's death as well as the moral distress that care aides report experiencing.

As part of this study, the care aides were asked to describe the relationships they have with residents. Just as there is no single type or category of resident, there is also no single type of relationship that care aides have with residents. Nevertheless, participants continually reported on how much they "love" the residents and how "they are the reason I stay." Sometimes care aides felt they were viewed by some residents as a grandchild and, in return, the care aides viewed the residents as grandparent-like figures. As one participant described:

> There's . . . a couple of [residents that] every time they see me, they will say, "Oh, is that . . . "? They will say my name. "Yes." And then, "Can I have a kiss from you?" . . . They always look for me, like—oh, it looks like they're my grandmother. [They love me] . . . I just can't explain [it] enough. It's just, I treat them like my grandmother, yes. **(Clare)**

This participant struggled for words to explain the relationships in detail, but it is understood that she cares for those residents as she would her own grandparents. Nine participants reported that one of the reasons they got into this field was because of the close, parental-like relationships they had growing up with their grandparents. Perhaps their relationships with residents are an extension of their relationship with their real grandparents, who are, in most cases, no longer alive. Regardless, this close, family-type relationship with residents was expressed many times, as with the following quote:

> I give a 110% to this place every day. I am extremely resident-focused. They're like my extended family. I take my job as a privilege. I'm very honored that I am allowed to become adoptive family to people, that people trust me with their loved ones' lives. I take my job very—to heart. It's mostly why I'm here. **(Shelley)**

Care aides commonly reported perceiving residents as *"like family."* Alongside this, many of the participants held the opinion that it was in return a privilege and honor to have the opportunity to become the residents' adopted family members. Even though care aides have been taught and encouraged not to form relationships with residents, they often explained that this is just not an option. Care aides deliver care to residents in the most intimate ways possible, and because of this participant reported that it is often *"impossible"* not to form emotional bonds and friendships with residents.

Although the participants commented on the closeness of their relationships with residents, it was also evident that the residents were care *"assignments."* A care aide may leave the facility once his or her shift is over; a resident may not leave. Helen, a 44-year-old Caucasian care aide with 8 years of experience in LTRC, described the love she has for the residents and how becoming friends with them "just happens":

> What keeps me going is that when I leave, I feel that I have done something. You know what I mean? I've looked after these people today. And I know they're clean and they have something to eat and, yes . . . I love them. And that's what keeps me going. . . . And I know they say that we shouldn't get attached or whatever. . . . And we're not here to be their friends. At a seminar I've gone to, I heard them say that you should not be friends with your residents. . . . Well, I mean the thing is . . . it just happens. You obviously took care of somebody in that personal aspect. You have to feel some kind of attachment. **(Helen)**

What Helen describes is particularly telling because she knows that she is acting in a manner that would be considered unprofessional based on her education, and yet she acknowledges the importance of forming an attachment in the "real world" of LTRC. This attachment, either as "like family" or as a friend, leaves the care aide open to emotional distress when a resident die, as described by Donna:

> He was my buddy. I called him Mickey-boo. He was really hard to deal with in the beginning when he was more mobile and all this stuff. He was just really demanding and really rude. But then, as time went on, he just grabbed my heart. He's just so sweet and he always kind of thought, like . . . He always talked to me like he knew me, like he thought I was somebody all the time. The same person, but just not me, but somebody, like, in his family or something. We just had these conversations. He just talked about certain things and I just go, like, that, I would say, "Yes, whatever," you know? And—yes. So, that was difficult. It's really difficult to lose somebody. **(Donna)**

Nearly every participant shared poignant stories about his or her relationships with the residents. It was apparent that many care aides, as well as many residents, clearly enjoyed working with each other and valued the relationships they had with one another. Patricia, a 42-year-old Caucasian care aide with 10 years of experience, described her relationship with her *"favorite"* resident, an older gay man who seemed to also value their friendship:

> Bryan a sweetheart . . . He’s been here, oh, we’ll I’ve been here for almost 8 years, so . . . and I think he’s only 77 . . . I think he’s got—I think he’s schizo. . . . Yes, and he lost his partner. His partner was a diabetic and he lost his partner, well, just before he came in here [they were probably together] oh, 20-something years or something . . . Yes. I know he was jealous because his partner was both ways [bisexual] and he’s not . . . He and I have great conversations. . . . Yes, he’s my favorite. He and I have been really close since I started here, yes. And whenever I come in, he’s like, “ . . . When are you coming back!?” **(Patricia)**

Ruth, a 40-year-old Caucasian care aide, also describes how she loves all of the residents she cares for:

> **Researcher:** Who is one of the best [residents] you care for?
>
> **Ruth:** They’re all pretty good. It’s just they’re all good in their own ways, so I don’t know. I don’t really have that favorite . . . I have my . . . Like, probably about 20 that I love a lot, and that I would go visit and make sure they’re okay if they’re down and what not. Like I’ve been here so long, so I kind of know everybody everywhere.

The literature on residents in LTRC stresses the meaning and strength of the social relationships between residents and care staff, but rarely is the reverse discussed. Care aides repeatedly shared the importance and depth of their relationships with some of the residents, as in the case of Patricia and Bryan.

Although all of the care aides discussed residents they felt they had established friendships with, not all residents were described as pleasurable to care for. Often participants talked about residents they genuinely cared about and had established relationships with, but who also had complex needs that had to be met and at times grating personality traits. Even in these instances, participants reported experiencing joy, humor, and empathy in their work. As one participant shared regarding working with a difficult resident: *“She drives me crazy. . . . I love her, but she drives me crazy.”* It is this capacity to be routinely agitated by someone and yet still feel affection toward the person that seems to be a genuine skill held by care aides.

Participants also reported seeing themselves in the residents they care for. One participant reported that she identified with a certain resident who was described as incredibly difficult by other care aides: *“[She] is a smart ass . . . So am I. So—that’s why* *we get along so well [Laughs].”* It is this ability to relate to a resident that may make for a more compassionate and understanding experience between care aide and resident.

Care aides described some residents as quite difficult to care for. These residents were often labeled as *“high maintenance”* or *“needy”* due to their long list of requests and demands that, from the care aides’ perspective, are not always necessary or in their job description. Participants described these residents as time consuming and often go against both what the resident and the care aide wants to do. It was discussed by participants how they perceived these residents as sometimes purposefully making their job more difficult because they are themselves unhappy. In the following quote, a participant with 7 years of experience in LTRC is very open about not enjoying the presence of everyone she cares for:

> We have residents that have mental issues. . . . They have cognitive problems, and they can be—I mean just today, I brought my resident out for breakfast. And he was there. And I said, “How’s your breakfast going?” And he said, “Why don’t you just fuck right off?” And I said, “Excuse me.” He said, “Get the fuck out of here.” . . . This is word for word how it goes down. And so I turned and said, “As a lady, I don’t appreciate when you use that word with me, but I understand. You’re probably frustrated. And I’m sorry that you feel that way.” And that is my response. In my heart, it hurts, but I know that at the end of the day, cognitively, he doesn’t mean to hurt my feelings. . . . So, even though there are people I don’t enjoy, I get that this is probably the last place they want to be. They want to be at home where their last happiest memory was. **(Donna)**

The interesting thing about this quote is that although the care aide admits the resident’s comments hurt her feelings, she reports not snapping back at him and instead brings herself to see where he is coming from. The care aide has the capacity to put herself in the resident’s position and meet him where she thinks he is—miserable in LTRC and not wanting to eat breakfast. Or perhaps this resident just did not like this care aide and found her annoying; we don’t know.

Difficult residents are also described by participants as those who have a tendency to lash out, either verbally or physically, at care aides or other residents. These residents are perceived to be combative for many reasons, and because of this care aides must proceed with caution. These interactions with residents will be discussed in greater detail in Chapter 6 of this thesis. The following story is from Patricia, who highlights her experience with a younger resident with Down syndrome:

> Lucy, she drives me crazy . . . I love her, but she drives me crazy . . . I don't know if she has Down syndrome. I know she had scarlet fever when she was [younger] . . . She's never been married, never had kids, never had a boyfriend . . . She can remember your name. That's one thing that she's very good at, is she can remember everybody's name. She looks at your nametag and she will remember your name. [She drives me insane] because she's so loud [Laughs] . . . She's got this squeaky loud voice . . . Because she—I think she's partially deaf . . . Sometimes, she's frustrating because, you know, she can remember everybody's name, but yet, like, for instance, in Bingo—she comes to Bingo and she gets so involved in Bingo and she will go to the bathroom [in her pants], and it's like, "Really . . . Why would you?," because she doesn't want to miss out, it's like, "Okay, Lucy you need to go the washroom." **(Patricia)**

This quote reveals how it is important for participants to know their residents' quirks and challenges to deliver the unique, often changing, level of care necessary. It also reveals how frustrating it is for care aides to deliver care to someone who they may not have a relationship with and how it is easier to care for someone when there is a relationship. This quote also speaks to the patience that care aides have regarding understanding and working with the residents' sometimes limited cognitive capacities (in this case, remembering to use the washroom). The following section outlines key areas in which care aides reported going beyond the scope of their care aiding role to ensure their residents quality of life, safety, and well-being.

5.1.1. Appreciation from Residents

The sense of appreciation that participants reported feeling from their residents both made the job worthwhile and helped position the resident vis-à-vis the care aide. The care aides spoke to their residents' level of appreciation for their care depends on four main factors: (i) level of care required; (ii) their cognitive capacities; (iii) their verbal capacities; and (vi) the attitude of the resident. Of course, there are also attributes of the care aide that will affect the level of appreciation that they will perceive from residents. These care aide attributes residents may perceive include, but are not limited to, the following: (i) the attitude of the care aide; (ii) the quantity of care delivered to the resident; (iii) the quality of care delivered to the resident; and (iv) their work shifts. Despite what factors are present when care aides do feel appreciated by residents for the work they do, their own morale is positively impacted. This is demonstrated in the quote below:

> [A permanent position] came up and one of the residents said to me, “You know that that [position] coming up?” I said, “Yes,” and he goes, “Are you going to apply for it?” I said, “I’m not so sure. Why? Do you want me to?” He goes, “Yes, because I think you do a lovely job. You and I get along quite well, and I would like you to work with me.” Coming from this resident, I was like, holy smokes! And then I told my [Director of Care] and she was like . . . “You do very good work. You’re very compassionate. And I can see why he would say that to you,” which made me feel good! **(Corrina)**

This story highlights the interconnected nature of residents and care aides regarding care delivery and attitude. The resident reported to Corrina that he thinks she does a great job and, in return, Corrina was encouraged to continue to deliver quality care.

Sometimes care aides would voice their frustration that they did not feel appreciated by residents. For example, Karen has been working in LTRC for a decade. She describes below how when she does receive a compliment from a resident, it positively affects her, but that those instances are few and far between and are often book-ended by violent or discouraging interactions with residents:

> It’s just nice when your resident actually says, “Oh, I think you’re the best.” You don’t get that very often in this job. . . . Not by residents, no . . . Yes, but not—generally not the residents. I mean, there’s—or I see, like, one of the ladies I was looking after this morning. I asked her to put her arm up on her armrest because if I touch it, she’ll hit me. And she says, “No, I can’t.” And I said, “We have to.” **(Karen)**

The quote above reveals how care aides reported feeling that their residents often do not appreciate the work they do for them. Although, when appreciation is shown, it is remembered and cherished.

Participants reported going beyond what they were (or in many cases were not) trained to do in school regarding delivering physical care and supporting their residents’ personhood. The following section will discuss how care aides reported completing extra tasks, not necessarily work based, to help facilitate the overall well-being and personhood of their residents. This section will include a discussion on care aides’ efforts to support residents' needs for entertainment, aesthetics, and romance, as well as advocate for their residents and protecting their confidentially within LTRC.

Promoting the Good Life: Entertainment, Aesthetics, and Romance

One of the routinely heard grievances from participants was that there was limited entertainment for the residents on a day-by-day basis. Although Green Lodge had, from the participants' perspectives, a *"great activities program"* and *"recreation therapy team,"* there was still concern among care aides that the residents had too much unstructured time when residents were appearing bored, agitated, or depressed. As previously stated, participants reported caring about their residents' well-being, and seeing them in a state of persistent monotony, frustration, or loneliness also affects the care aides' well-being. If the care aides see that a resident's personhood is not being cared for, they reportedly work to rectify the situation as soon as they are able. Participants spoke at length regarding what they have done and what they wish they could do to provide entertainment and activities to remedy the situation they often see their residents in. One apparently exceptionally extroverted care aide described how she will go to great lengths to lift the spirits and entertain the residents throughout the complex care dining room:

> Everybody deserves to be engaged all the time. So my personality is a slight bit different where I am an extroverted person. . . . So it's down to singing. If the mood strikes, that's what we're doing. If we're goofing around, having a joke, that's what we're doing. If I sense agitation, then I'm quieter and more compassionate. It's just always about who I have with me at the time. And at sometimes, I'll even encourage the whole dining room to get involved like with the singing or a dance or a little bit of performing on my part. I'm kind of in the best place as possible for my personality [Chuckles]. Exactly, what took me this long to get here is the problem. **(Sharon)**

By entertaining the residents, the care aides are also able to create positive diversity away from their scheduled task-based care routines. In this way, the care aide can participate in a creative activity outside his or her assigned tasks and the resident benefits by being entertained. It is thought that in this way both the personhood of the resident is being recognized, by having entertainment brought to him or her rather than being in a state monotony, as well as the personhood of the care aide, because she can act in a way that facilitates her joy.

It was apparent from the care aides' perspective that even task-based duties extended beyond simply addressing physical needs. Another duty that was not a part of the original interview guide but that participants discussed at length was the appearance of their residents. Although ensuring the residents are groomed, dressed, and bathed is a task-based duty, participants reported taking extra pride in this work. They discussed how they would ensure that their residents looked clean, dressed, groomed, and well cared for and that these were facilitators to maintaining relationships with residents. Here, task-based care extends broader than simply addressing the residents' physical needs. As Donna, a 32-year-old Caucasian care aide with seven years experience explained, it does not matter if the resident is at the end of life; his or her aesthetic appearance and the cleanliness of his or her room are paramount to the delivery of good care.

> I'm so particular and I like my residents to look great. Even when they're dying and—You know, like, it's just one of my most favorite things to do, like, just to make them look comfortable, make them look good. Doesn't matter if they're dying, you know? Like they still need the care as if they weren't dying. Yes. So, when somebody walks into their room, I expect the room to look perfect and the resident to look perfect, even when it comes to the sheets, when it comes to their surroundings. You know, I hate all these clutter and everything all over the place. I'll literally be going around and cleaning up. Like I have a little bit of OCD anyways [Laughter]. **(Donna)**

In this quote, Donna is open about how her actions are based on her needs and not necessarily the residents'. She jokingly makes fun of herself by saying that perhaps it is because she has obsessive compulsive disorder, but it could be that, as a woman in her early thirties, she personally cares a great deal about appearances and, because of this, it translates into the "extra" care that she delivers to her residents because she sees value in it. Regarding the appearance of residents, participants would make comments about other care aides not being considerate of their residents' appearance or the cleanliness of their rooms. It seemed that to many of the participants, well-groomed residents were equivalent to well cared for residents and, as such, if a care aide had residents who looked ungroomed, that may translate into them not delivering good care. This evaluative component did not change irrespective of what the resident's stage of life was. This sheds light on the notion that although relationship and sense of attachment were important, at the day-to-day practice level appearance was how good care was judged (i.e., how the resident was dressed and his or her room presented). This is what provided the evaluation as to whether the care aide was doing a good job or not.

Participants reported caring for residents' sexuality and helping to ensure the romantic relationships they established in LTRC were supported to the best of their abilities. When one participant was asked what she thought about residents partaking in romantic or sexual relationships with other residents, she reported: *"I think residents are going to do what they're going to do. And I think they're still alive. Let them do it . . . they're not dead. As long as they're not being inappropriate in front of people . . . I think it's totally cute . . . They're human. And if that's what keeps them going, let it happen."* This quote highlights how care aides empathize with the residents' current situation and understand that sexuality is a common part of human nature. The residents may want to and can engage in this behavior if everything is safe and consensual. It needs to be noted that this participant's language describing the residents' relationships as *"totally cute"* sounds dismissive and not respectful of two adults in a relationship.

The following account from Patricia describes a recent romance between two residents at Green Lodge. Nancy and Barry (names have been changed for their confidentially) had been found in each other's rooms participating in intimate acts.

> Nancy and Barry . . . I think [Barry] was in his late 70s . . . and I think. Maybe, no, she was probably in her late 80s—No, middle 80s. Okay. So, they're both married [but not] to each other . . . He was a bit more—like he wasn't totally demented. He could still have a little bit of, how do you say . . . ? [Cognition] yes, like he knew right from wrong, still, you know what I mean? . . . Not fully cognitively impaired . . . She, on the other hand, did not . . . She was like in the—yes, yes [stage] . . . I think she passed away just after that, like she could still walk and talk, but she wasn't really, I don't know, but she had enough gumption to go in his room . . . I'm not sure if it was a regular thing, but I know they did get—I know that they did get caught . . . She [snuck] into his room. Whether it was by accident or not, he was like, "Come on over." . . . The care aides caught them and I'm not sure how far anything went, but—because they had to try and separate them because the wife and the husband—they were scared that they were going to come in at some point and catch them. So, they really—we really had to—keep an eye on them . . . They were both married to other people. **(Patricia)**

This recounting of Nancy and Barry's experience highlights how care aides are often placed in ethically challenging situations when trying to ensure that all aspects of their residents' well-being are accounted for. These situations can get even more challenging when the needs and concerns of the family of residents must also be taken into account. For instance, the issue reported by Patricia was not that the residents were not having a good time, it was that the care aides were concerned for the well-being of the residents' spouses. As Patricia stated, the spouses of the two residents regularly visited Green Lodge and likely neither spouse would approve of their extra-marital affairs. If their spouses were made aware of the events transpiring between the two residents, the care aides predicted it would lead to undue stress on all of the characters involved: the care aides, the residents, and the two spouses. In this way care aides are caught between wanting to facilitate their residents' well-being and allowing them to behave as independent adults, yet they must constantly keep in mind the other issues at hand and navigate their relationships with all of the other participants in LTRC and modify their actions accordingly.

It was evident that participants also cared about the residents' complex human needs that extended past what was contained in their charts. From ensuring that the residents have some form of entertainment, even if it ranges from care aides making a 'scene' to confirming that this research project will keep the information about their residents confidential and safe, to supporting romantic relationships that blossom on the complex care floor between residents. Participants reported doing what they could to facilitate their residents' well-being. In this way, it may be perceived that care aides act like gatekeepers for their residents to the world outside of LTRC as well as gatekeepers to a more resource- and stimulation-rich world within LTRC. Considering this, the following section will discuss situations in which care aides needed to intervene to prevent or stop the further mistreatment of residents.

Protecting the Residents: "If I am not here, he would have died!"

The previous section described some of the situations where care aides go beyond what is asked of them in their care charts to facilitate what they perceive is a better quality of life for their residents. The following section will discuss situations where participants reported going beyond their assigned tasks to prevent any undue harm or neglect to their residents. Participants shared stories of advocating on their residents' behalf when they witnessed mistreatment or the delivery of poor quality of care. Alongside this, participants shared their accounts of speaking up on their residents' behalf and the consequences that followed such interventions. The following story is of a care aide who realized one of her residents was a remarkably slow eater and due to the rushed pace of the facility, he was not allotted the amount of time necessary to eat. Because of this, he became malnourished and nearly died. The care aide intervened and educated the nurse as to how this resident does in fact eat, but that he is just an incredibly slow eater:

> And one guy . . . took the full 45 minutes [to eat] because he was just an incredibly slow eater. The nurses cracked down . . . and kept reporting he wouldn't eat. "He won't eat. He won't eat. He won't eat." He [went on] the palliative list, he almost died. I got mad. I went to one of the nurses, and I said, "He absolutely will eat! They're just not taking the time to do it." And I brought her with me. I made her come to me [Laughs], and sit there and watch for 40 minutes while I fed this guy . . . I made that nurse come down and watch, watching me, the whole thing. And then she finally cracked down on the other staff and said, "You are not allowed to put him to bed for dinner anymore. He has to be out in the dining room. And he has to be fed." He lived for another year and a half . . . He was totally okay. He was just a slow eater. . . . He perked up. He started eating by himself again. It got to the point where they could just bring him out in his wheelchair and he'd sit there and eat, because he was starving. And that's one of the things, what I mean when it's like, I, part of the reason I'm still here is because if I'm not here, he would have died. **(Jane)**

This story details the frustration that this participant felt when seeing her resident was starving due to a lack of patience and understanding by other members of the healthcare team. This story also highlights the "heroine" story—*"If it wasn't for me, he would have died."* This shows that the care aide knew what was going on and when they finally listened to her, he got *"lots better."* From Jane's perspective, if she had not stepped in and advocated for her resident, she believes that he would have died much sooner. She reports that it is stories like this that keep her coming back to work. She feels that if she does not advocate for her residents' care and safety, no one else will. Participants reported being frustrated, and sometimes outraged, by the dismal care or neglect that they perceived other members of the healthcare team were delivering. They perceived their duty to be not only to deliver care, but also to advocate for their residents when they see them being treated poorly.

Alongside concerns about the safety of their residents was the care aides' need to ensure that their residents' privacy and confidentiality were met as well as to show that they were aware of the policies and practices that guide their role. In many of the interviews, participants were concerned that the anonymity of their residents would not be respected. Care aides wanted to participate in interviews, but they also wanted to ensure that their residents' information was going to be safe after their interview. During one interview, a care aide began discussing a sensitive topic related to one resident when she stopped midsentence and asked, *"Are we allowed to talk about [this]?"* She was understandably concerned that what was said during interviews would be shared with others and the confidentially of the resident would be at stake. In these instances, what was suggested was that the care aides could change the names of the residents. For the remainder of this specific interview, it was apparent that this participant used aliases when discussing her residents. It was a thoughtful gesture on the care aide's part that also added a level of complexity for herself because she had to remember many seemingly random resident names to continue discussing those she cared for. The following section will elaborate on suggestions that care aides reported in relation to their ability to deliver quality care and to increase the residents' complete well-being while in LTRC.

5.1.2. Relating to the Residents: Suggestions for Improving Residents' Quality of Life

Participants often shared suggestions on how to improve the delivery of care to residents and increase their well-being. This is clearly a topic that care aides spend a great amount of time thinking about and deliberating with their colleagues about. Participants discussed how they generally do not get an opportunity to discuss with researchers or decision makers their thoughts on LTRC transformation or that when an opportunity does arise to speak to decision makers about these ideas and requests, nothing appears to happen, so the care aides continue to feel unheard. Regardless, participants were open and enthusiastic to report their own ideas for how to improve LTRC for the lives of their residents. These suggestions include allowing care aides to have more autonomy over the residents they care for, reducing the systemic task-based focus found in their assigned checklists, and increasing the number of social health supports for their residents. Finally, this section also includes a discussion surrounding relational versus task-based dementia care.

(i) Autonomy Needed: We Know Our Residents Best

Care aides report having tacit knowledge that they believe would enhance the personalized care delivery to residents. Tacit knowledge (as opposed to formal, codified, or explicit knowledge) is the kind of knowledge that is difficult to transfer to another person by means of writing it down or verbalizing it. Participants perceive that because of their low rank in the healthcare hierarchy, they report feeling that their input is left unheard and they are instead re-directed to complete the assigned tasks in the manner prescribed to do so and without deviating. A common suggestion from participants was to make room for care aides to have more autonomy over those they care for and to trust the care aides' tacit knowledge regarding their residents' health and well-being. The following account is from Jane, a 25-year-old care aide with 5 years of experience at Green Lodge. She shares a dramatic situation she encountered and the frustration she felt when her voice was not heard, and her resident, she believed, suffered because of this:

> To me, it just makes me really sad. It sucks that I can't do anything to help [some residents]. More so than that, I get frustrated that no one else seems to know what to do. I've had panic attacks, so I know how to identify them. I know what kind of stuff can help. We have a woman right now actually who they've been reporting for weeks as having seizure activity. It's not seizure activity. . . . They are panic attacks. And they are clearly panic attacks. She screams and swears and says stuff to you . . . It's not a seizure. It is a panic attack. I went in there. And she's sitting there. She'd go, "Oh! Oh! Oh!" And I asked her, "What's wrong?" "Someone's coming at me. I'm scared. I'm scared." That's not a seizure. That's a panic attack . . . I opened the window, I sat her up, I put very cold water on her forehead because that always worked for me. Two minutes later, she stopped . . . And [the nurses] give her pain medication—to manage her pain and saying she's having seizures. And I've been saying for a couple of weeks, they're not seizures. They're panic attacks. [And the head nurses says] "Well, you're a care aide." I know what a panic attack is. And I'm telling you. Like it's so frustrating that something so simple is being misidentified and mistreated. **(Jane)**

Along similar lines of having their voices and perspectives unheard, care aides also discussed the frustrations they feel by having to complete a mandatory task checklist on every shift. This checklist covers all of the "tasks" that care aides must complete during their shift. They reported that although they recognize it is an efficient, organized format for getting tasks accomplished, they perceived these checklists as not conducive to facilitating the delivery of good, personalized care. Specifically, participants described that one of the most frustrating things about their job was related to the discrepancy between how the policies determined allocation of their time and what they perceived as the most important tasks at hand to ensure residents' well-being. Often these policies are in the form of checklists that outline what tasks must be completed. Participants did not use the term *person-centred care*, but in its place was often *client-centered* or *individualized care* for residents. Regardless of the terminology, care aides reported believing that the checklists inhibited the delivery of "good" care to their residents. As one participant with 5 years of experience described:

> I think one of the biggest things that they really, really, really need to reinforce is that it's not about tasks, it's about people . . . everything is so focused on, like, a checklist. "You need to do this, and this, and this, and this." And the actual residents are completely forgotten. What they actually want is never a question. **(Jane)**

In this quote, Jane is frustrated that not only is her knowledge of her residents disregarded, but also that the requests from and wants of the residents themselves are also left unheard, unrecorded on the checklist, and ultimately ignored. The frustration care aides expressed regarding the dichotomy of wanting to provide what they perceive is the best care for their residents versus it being incongruent with what the task-based care needs are. Care aides returned repeatedly to their frustration with the personal, important information they receive directly from delivering care and interacting one-on-one with residents not being used in any capacity nor shared from care aide to care aide or from shift to shift. As one participant with 8 years of experience explains, *"this is the part of the job that I don't like, is that they make us very task-orientated. Like, you have this many people to do this today and no matter what, it's going to be done."* For example, participants regularly discussed not wanting to let their residents sleep if they desired to do so. For one care aide, it may be "good care" to leave a resident in bed if he or she does not want to get up for breakfast. For another care aide, it may be good care to make sure that a resident is up and dressed for breakfast, whether the resident has requested to stay in bed or not. As one care aide explained, *"you know that [if] our residents are not feeling right or they're tired, we just let them sleep. We are all like that . . . Most us we'll just let them sleep and get them up after . . . This is their home. If they don't want to get up, [we are] not going to force them to get up."* Sometimes, their residents just want to sleep in, stay in bed, and not partake in breakfast with the other residents, and this should be allowed. Care aides recognized this is a normal, human behavior and by allowing residents this option to stay in bed, if that is what they wish, they are facilitating good care and, as such, their residents' personhood.

This draws attention to the day-to-day power issues that left care aides feeling discounted and unheard. The discrepancy between letting residents sleep and forcing them to get up for meals is also dependent on who is the head nurse on a shift. The care aides are aware of this and act accordingly, usually despite what they personally believe the residents would rather have happen. As one participant discussed that *"some nurses are like, 'No, they get up.' You know, 'Don't leave anybody in bed.' And some are like, 'If they're sleeping, let them sleep. Give them a tray.' And then some nurses are like, 'No, no trays unless you know there's a good reason.' So it all depends on who the nurse is."* This quote details how care aides, although believing that they know their residents' direct care needs best, do not have autonomy over the nuances of the care delivery or the sequences of tasks that must be accomplished; they must listen to many different and varied directions regarding what is "good care." This account also makes apparent the flexibility care aides have in terms of who oversees their work and how their care delivery is often dependent on the differences in the head nurses' perspectives of what is good care and what tasks take precedent.

As one participant explained, sometimes care aides will make a conscious choice not to listen to the head nurses' requests to deliver what they feel is the right thing to do regarding their residents' care: *"Some nurses will let us [let residents stay sleeping] and others don't. But my theory is as long as they're sleeping, I'm just going to let them sleep. I'm not going to get them up. They're like 80 and 90. They can sleep if they like and we'll get them breakfast, lunch when they're ready."* Although some participants reported partaking in actions such as this that allowed them to claim their autonomy over their residents' care, these decisions were not taken lightly. Participants discussed how not following the head nurses' directions can place care aides in an unfavorable light with the head nurse, which can have unfortunate repercussions for the care aides work life, which will be reviewed in detail in the following section.

(ii) Social Health Supports: Programs and Engagement Necessary

Care aides felt they often served as both a care provider and a social support network to their residents. Unfortunately, however, the tasks of providing care often seemed all-encompassing and did not leave room for social interactions with residents. To complete both the care aide and social support roles, participants reported multitasking their socializing time with residents with their task-based caring duties. As one participant reported, *"I find once you're in the real world [not in school] you don't have that extra time where you get to just sit and really chat with your residents . . . It's really kind of learning to, like, talk and work as you go."* Care aides expressed discouragement that currently there are not better options to offer their residents in terms of venues for social engagement and activities, but they do have ideas on how to remedy the situation. As Sharon, a 39-year-old Caucasian participant who has one year of experience as a care aide, described:

> Our activity program really is what sells a lot of people who want to be here because we have a really good activity program . . . If it's something that tells me, that sticks out, over and above is that this activity program here has way more passion than the one that—like there's still activity people there, but that building doesn't give as much money as opposed to this building seems to figure out ways to create money that isn't there . . . They're always looking for a way to make something happen for the seniors or the residents so . . . The other facility was just, like, "Oh, budget's run out." [And the Recreation Therapy Manager is like] We'll find [a grant] or we'll make calendars or we'll sell wall clocks or hangers, like, whatever, right? **(Sharon)**

It was clear from the interviews that participants admired and respected the resiliency of those involved in the activity program at Great Lodge. The creativity of the Recreation Therapy Manager was discussed and appreciated. The participants saw her as constantly searching for funding opportunities to help the program grow and thus engage more residents in meaningful activities. The care aides see the effort and enthusiasm that is generated by those in the activity program as directly increasing the residents' social engagement and quality of life. Helping the residents with this level of engagement is something that care aides reported wanting to do but not regularly having the capacity to fulfill due to their already heavy workload. By seeing that there are other venues for residents to have their social well-being needs met allows the care aides to focus on their defined role, care aiding, and alleviates the moral distress they feel when they cannot meet all of their residents' needs. The greater impact of moral distress on care aides will be discussed in detail in Chapter 6.

Along the same lines as increasing activity programs for their residents, participants also reported feeling discouraged about the lack of social engagement that was available for their residents. Nearly every participant mentioned the frustration they felt with there not being more opportunities for their residents to engage with other humans. Participants spoke about wanting to *"sit, gossip, and paint [the residents'] nails,"* but due to their overwhelming task list, the complex needs of their residents, alongside regularly working short staffed, these were not activities that they could engage in with residents. During interviews, participants offered their thoughts on how to increase the social engagement of residents. Ideas such as bringing in more student volunteers and hiring private companions to come and socialize with residents and take them on outings were two that were commonly brought up. One participant reported her idea to *"take the hours that [nursing students] have to do for their nursing practicum and to get accepted into the nursing program, and to use those for going into [LTRC] and [socializing with residents]."* This idea highlights care aides' creativity and desire to find viable solutions to facilitate the social engagement of their residents.

5.1.3. Relational and Task Based Dementia Care

The topic of dementia was continually so intertwined with the study interviews and observations that it was impossible to separate. The following excerpt is from an interview with Shelly that was conducted in June 2016. This participant was interviewed the previous fall in October 2015 and since that interview became a strong advocate for other care aides who participated in this study, often encouraging her friends and fellow care aides to be interviewed by me. This particular evening shift, Shelly appeared happy and enthusiastic that I follow her around:

> When I was following Shelly around, watching her do care, something else interesting happened: a resident who soiled her bed was so worried she was going to "lose her room." She kept on asking Shelly if she would be kicked out—she was so very concerned. Shelly was very sweet with her and kept on saying, "*No, mumma, you have paid until the end of the month. You are fine, you have this room until the end of the month, you are paid until the end of the month."* The thing

> that stuck out to me is that Shelly brought up the payment schedule of the room to the resident. This resident was just lying in her soiled bed with advanced stage dementia—why Shelly thought bringing up room payment was going to be understood by this resident and calm her down and not confuse her even more confuses me. Why not just tell the resident, *"No, mumma, you are fine, everything is okay"*? Why risk confusing her with thoughts of payment and monthly rates and all of that? Does this show a lack of comprehensive understanding in communicating with people with later stage dementia? **(Field Notes 06.22.16)**

It was apparent that although during interviews care aides predominantly spoke about how they felt confident in their ability to deliver good dementia care, perhaps they meant task-based care because during observations it was not always clear that the relational side of dementia care was at the forefront of their care delivery. This excerpt also shows the temporariness of the resident living at Green Lodge. Through her dialogue with the resident, Shelly is reinforcing that this place is not the resident's permanent home. It represents the commodification of LTRC and that a bed may become available for a new resident relatively soon. Shelly's response also represents that she thought she was doing a good job by telling the resident that her payment had been made and that therefore she would not be kicked out. Instead of helping, Shelly could have been distressing the resident even further.

It is apparent that care aides are concerned for both the task-based needs of their residents as well as their residents' overall well-being and relationships. Participants reported having strong relationships with their residents, despite having been advised against this. They describe going beyond the scope of their pre-defined care aiding role and doing all they can to advocate on behalf of their residents and to facilitate their well-being despite the barriers that stand in their way. Although the relationship between residents and care aides is clearly directly related to care delivery, the care aides' relationships with the other participants in LTRC also affect care delivery. Due to the nature of the role of care aiding in LTRC, participants reported spending as much time with other care aides as they do with residents.

5.2. Relationships with Fellow Care Aides

Care aides and residents are closely intertwined, and they encompass the two largest groups of characters found within LTRC. As seen in the previous section, care aides had strong opinions regarding those they care for, and the same is true about their closest co-workers, their fellow care aides. Participants reported many positive aspects regarding working with their fellow care aides, but the amount of time they spent sharing frustrations about their colleagues was telling. It became apparent that although care aides work with partners, it is their fellow care aides who participants view as one of the main barriers to care delivery. This section will begin by reviewing the main overarching types of difficult behaviors of care aides that the participants found challenging to work with, as well as how these behaviors are perceived to impact the care that they are able to deliver. Next, an overview of the predominant positive aspects of care aides will be presented, including a discussion of which characteristics participants described as beneficial to their own delivery of care to residents.

5.2.1. Supportive Care Aides

Participants reported respect and admiration for their fellow care aides who appeared to share the workload equally, deliver good care, and behave positively and respectfully to both staff and residents. During interviews, participants were asked to describe the characteristics that they view embody the best care aides they have worked with in LTRC. The patterns found in their answers overwhelmingly pointed to the importance of a good attitude and the ability and motivation to be a team player. The best care aides were perceived to be those who had a positive outlook on their work and were willing and able to lend a hand to others. Some of the most revealing and well-articulated answers to the best care aide question are reported below.

Participants discussed how one of the key reasons they survived *"going in blind"* is that they worked with fellow care aides who were kind, patient, and understanding about the difficulties of their situation and, as such, they helped facilitate an easier transition from the school environment to LTRC. The following quote is from a care aide who has been working in LTRC for a decade. It is important to note that despite her 10 years of experience, when asked to describe the best care aide she has worked with, she immediately recalled her initial entry to LTRC and the woman who initially oriented her to her new role as a care aide:

> [The best care aide I have worked with was] smart, caring, very easy to talk to. If you have any problems—I don't even know how to explain her. She's just—well, when I first started here, she's been here a long time. When I first started here, I lost my first resident in my arms with her. She was in there, but—she walked me through the whole thing. She was just—she's calm, cool, collected . . . She's just that person that you know if you had any problems or anything, you could go and talk to her about it and she'd try and help you. **(Patricia)**

It was apparent from many participants that what makes fellow care aides the most enjoyable to work with is two-fold. First, they are enjoyable to work with, their attitudes are positive, they can make light of a negative situation, they work hard and efficiently, and they help each other out in the process. They are a team player. Second, they deliver good, safe, thorough care to the residents. The notion of being a team player as an aspect that embodies good care aides was brought up in the interviews repeatedly. Participants reported believing that their fellow care aides are there for each other and they work together as much as possible to support one another. As one participant said, *"we stick together . . . and we stick up for each other."* Another participant described, regarding certain residents who rarely receive visitors, how care aides, as a collective, offer their individual support to these residents: *"There's people here that haven't seen family in—ever. So, I mean, they get extra hugs. They get extra love. And for the most part, most of the care aides are like that with them as well. Like, we all recognize that. That's where as a team we're really good."*

A huge amount of respect is shown for care aides who are team players and have positive attitudes. However, not all care aides were good to work with. The importance of the peer relationships on the floor was highlighted by most of the participants. Strong team dynamics with other caring care aides appear to be an important part of having a positive care aide experience. However, there was also discouragement and frustration felt by those who did not embody these characteristics. When one participant was asked how many people she worked with who were similar to *the best care aide* she had described, her answer was simply *"I wish there was more."* When it was pointed out that, technically, that was not an answer, she laughed and said: *"Yes, I know."* Still, the dire situation that care aides are left in when they are partnered with a co-worker who doesn't work as a team player is unfortunate. As one participant elaborated, *"We don't function if we don't work as a team. And if you do have somebody that isn't working as a team, then usually that's what makes our day a bit harder. So it's very important."* The importance of team work and a good attitude among care aides was stressed in nearly every interview. Participants reported that *the best care aides* they worked with were accountable, and they could be relied on to show up for their shift, to deliver good care, and to help when needed. Accountability, from the care aides' perspective, refers to the trust that they will show up on shift and they will not force team members to work short or with a casual worker. As one participant explained, she often hears people complain *"Short staff, short staff. We need more money to get more staff."* She elaborated by saying that from her perspective*, "this isn't actually the problem. The problem is that care aides need to "show up for their damn shifts."* She believed that the issue of being short-staffed stemmed from a few care aides who she described as people who *"habitually call in sick."* When a care aide calls in sick, participants report that the entire floor is affected. The schedule is changed and if a replacement is not found, the care aides work short staffed and those who do show up for shift work harder. On the other hand, care aides who do not take sick days are reported to be appreciated by participants. Their fellow co-workers can trust that these care aides will do their work with them during their scheduled shifts. Despite the difficulty that comes with working with less than adept care aides, participants routinely shared their stories of admiration and appreciation for the best care aides and their desires to emulate the positive traits they have seen in these individuals. The following section will describe questions from participants in relation to improving care aide cohesion.

5.2.2. Difficult Care Aide Behaviors: Not Pulling Their Weight

The most common disagreement reported among care aide colleagues is when one care aide believes that a resident's well-being or safety has been put in jeopardy by another care aide's work. Care aides work in pairs, usually with one assigned partner and depending, on staffing ratios, a "float," who is a care aide who helps the others with their assigned resident tasks. There is discrepancy among the participants in relation to the perceived value of some of their fellow co-workers. Several scenarios were identified by different participants as particularly difficult. First was absence from work. It was reported to be common practice among care aides to *"call in sick"* when scheduled to work a shift with a care aide who was deemed difficult. As one care aide reported, *"we've had people ask, 'Oh, who am I working with? Oh, I'm not coming in today.'"* Unfortunately, some care aides were perceived to be so difficult to work with that their colleagues would choose not to come into work because the challenges that are assumed to present themselves with these difficult care aides far outweigh even the basic financial incentive of working a shift or the risk of being reprimanded for missing a shift. This participant continued by saying that *" . . . now the schedule does not go up until the next morning. So you find out whom you're working with, because we've had people call in, 'I'm not coming in because I'm not working with [that care aide] today.'"* From this excerpt, it is apparent that *"calling in sick"* to avoid a difficult co-worker happened so regularly and was causing large issues in staffing and workload for the care aides who did come to shift that the management had to intervene and stop revealing which care aides were on shift together until directly before that shift. Interestingly, it appeared from the management's perspective that it was easier to hide the information from the care aides regarding who they were booked to work with, rather than intervene with the specific care aides who were perceived to be difficult to work with. Therefore, from the perspective of the care aides, difficult care aides are intrapersonal barriers to care delivery. Participants were adamant that working with some of these difficult care aides was a detriment to the other care staff as well as to the residents in their care, but also the entire floor suffered. As one participant explained,

> People are calling in sick the days [difficult care aides] are working. And it was happening a lot—people weren't coming to work. We were getting residents more agitated, more injuries, more falls because people were so worked up [the worst care aides] affected literally everything . . . One person can really screw up the whole floor. **(Jane)**

Another common behavior that participants reported finding frustrating and a barrier to their care delivery was participants who were seen to *"know the system"* and who would do *"as little as possible without getting fired."* Participants reported that often these care aides will do enough care to cover the very bare minimum of residents' needs, and the company's requirements, but they purposely will not work fast enough to offer help to other care aides or deliver extra care to residents. As one care aide put it, they are *"really slow . . . It's going to be [a] tougher day because you're going to have to go and pick up most of the slack on their end."* To motivate and put pressure on *people* to equally contribute to the tasks at hand, care aides report being *"forced"* into the role of *"nag." "I've become the nag . . . I'm so tired of cleaning up for all of them. I can clean up after the residents. That's enough. I don't need to be cleaning up after my co-workers."* Participants reported feeling exhausted and powerless to force these care aides to pull their own weight on the team. Participants reported wanting to deliver the best care possible to their residents, but without the assistance of a partner who matches their efforts, they feel defeated and drained in their attempts to cover the tasks of two people. Betty, a 52-year-old Caucasian care aide with an impressive 30 years of experience, described what appeared to be an unfortunately regular occurrence:

> Oh, yes, I mean I try to say my piece and then grumble over, you know. And then I go on and I do it. . . . It's not going to change, like, sometimes we're going to be working with aides that don't carry their weight. And even if you say something or help them, right? It just doesn't change; you've always got to pick up, you know? And that's where I get frustrated here, because the workloads, I already have, you know? . . . And when you have to start doing that, you're exhausted. **(Betty)**

Betty describes how she has tried multiple solutions to remedy this situation, including speaking to the care aides or reporting them and trying to help them learn how to work faster, but she feels that she comes up against barriers that she does not have the power to overcome. Ultimately, just as Betty has done, many care aides reported accepting the fact that there will always be co-workers who simply do not pull the same weight as the rest of the team does. As one participant described *"That's just the reality of any job. You're going to have lazy ass workers . . . that make the same money as you that don't do the work."* Still, another participant described how *"we have a huge workload already. And to have someone that does a quarter of the work that gets paid the same wage is frustrating and irritating."* This understanding that even though one person may be more skilled, quicker, and harder working than the other, they all get paid the same was a reoccurring lament among participants. A 33-year-old male care aide with 8 years of experience recounts some of the things he finds difficult in his role care aiding:

> It's really tough to work with a bunch of ladies under one roof and not having overhead lifts, and injuries, and being rushed, and not having time for this and that. It's just really a go-go job. And so, when you have 70 women under one roof, and half of them are bitches. It's just horrible because a lot of times the women work better with the men. . . . I don't know what you have to do to get fired here because they don't fire too many people. **(Chuck)**

Chuck appears to be feeling powerless in his current position. He is working in a setting where he believes he does not have access to resources to help him do his job properly, he believes half of the people he works with are *"bitches,"* and he feels helpless to change anything because he does not see management stepping in to reprimand anyone. When care aides do not pull their own weight, everyone can struggle because the problem is that everyone is already working with scarce support as it is because the LTRC environment is under-resourced. Heather, a 26-year-old Caucasian care aide with 2 years of experience at Green Lodge, shares her perceptions of working with fellow care aides who deliver *"abrasive"* care to the residents, as well as what it is like to work with new care aides:

Researcher: Just think of one or two of the generally most difficult care aides you have to work with. You see them on your shift and you're like, "For the love of . . . [Laughter]

Heather: "Not again."

Researcher: What about with those people? But what do they look like as far as their care aide role?

Heather: Loud and maybe abrasive and don't really communicate with you as far as duties or what you guys have to get done throughout the day. They just kind of go and do their own thing and don't . . .

Researcher: Don't help you?

Heather: They don't help, yes, I guess. Yes.

Researcher: Any difference in education or anything? Has nothing to do with that? What is it? Just . . .

Heather: No, I don't think so, or if it's somebody that's, I guess, newer and don't really, like they . . .

Researcher: They don't know?

Heather: They're really slower. It's going to be your tougher day because you're going to have to go and pick up most of the slack on their end kind of thing, yes.

Researcher: And then do you—I don't know how it works. Are you mad at that person or you're just like this is . . .

Heather: No, I mean I'm not mad. I mean I was new too, so I've got, you know, seen some figures to what they're going through. I know it's not easy, especially if you're casual and you're on the wing for the first time. Like, I've worked with my residents for two years straight in that wing. I know their care—like the back of my hand, right? These people will have to go take the time to really go through everything and make sure they're using all the right equipment, and, like, it takes more time. It's going to take more time. So, yes, I'm not mad at them.

In addition to those who simply don't pull their weight, dangerous or neglectful behavior was reported to be difficult for care aides to work with. Participants describe how they are constantly aware that although they may deliver good care to their residents, there are other care aides who behave precariously and who may not have the residents' best intentions in mind. This dangerous behavior can been seen as a care aide delivering poor care or intentionally neglecting or abusing a resident, as Helen describes:

> [The worst care aides are] disturbing. [They are] very unsafe and rough with residents, [enough to make me uncomfortable] to the point of almost being in tears over it. That if I need help, I will not ask her for help with the resident . . . I will find somebody else . . . **(Helen)**

When asked if most of the care aides she worked with were good with residents, one participant responded that *"most are, but there are some people that really need to find something else, like they're not very nice to people . . . "* A care aide with this behavior can be seen as someone who is rough with the residents and disrespectful to the other members of the healthcare team, which can prevent accurate and timely communication between team members or the safe completion of tasks. One participant reported witnessing another care aide *"belittle the residents"* when delivering care or *"move quickly"* and *"roughly"* with residents and not deliver care at a pace that appeared to be comfortable for the residents' needs. Patricia described the apparent struggle for everyone involved when working with a care aide with these dangerous behaviors:

> Everybody that works with this person complains about her . . . she never smiles. I've seen her as a little bit mean to certain residents . . . she just kind of talks to them not so nicely and very pushy with the residents. And not a lot of people like to work with this person. She has had so many complaints**. (Patricia)**

The individual who Patricia is discussing had caused a great deal of stress and discomfort at Green Lodge for the care aides and apparently to the residents as well, since at the time of this analysis she already had numerous complaints against her. There is a clear disconnect between the care aides relaying information to management in the form of reporting and then action taking place, such as in Patricia's example, as she perceived the *bully as* not having been reprimanded. Ultimately, if care aides continue to report about an individual *bully* but nothing happens, this may lead to the care aides losing any sense that they have the power to make changes in the LTRC setting and that perhaps management is not concerned with their qualms. Despite whether reprimanding the *bully* will happen or not, this perception of nothing being done may ultimately lead the care aides to lose respect and trust in management. As Betty described, she knows that new care aides have "a three-month probation period, and I don't see it being utilized enough."

It was a discussion topic among some participants too that they believe bullies are in the wrong vocation. The essence of a care aide is to care for another person, and if a care aide lacks the perceived ability to care, then perhaps he or she should find a different occupation. As Chuck explains:

> **Chuck:** You don't do anything and you just screw everyone over. I just know that this person just thinks of herself and nobody else. So, for her to respect someone else, I just think she's not in the right job . . .
>
> **Researcher:** It's not even in the right job?
>
> **Chuck:** Not even in the right field, job. No.

The general perspective from participants is that some people are just not cut out to be good care aides. Participants can clearly articulate what makes a good care aide and what is going to prevent someone from being a good care aide. This participant identified respect as being a necessary trait to be good at care aiding. Participants also reported that some individuals do not have the capacity to be a good care aide. Whether this was the case because of a lack of training, accountability, or physical or intellectual capacity was not known to the participants. Jane recounted one of her experiences working with someone who she believed did not have the intellectual capacity do be a care aide:

> We had for a long time—we had, just about every day, we had six or some things to report him for unsafe practice. Nothing happened. We were literally told by the DOC at the time that she didn't want to fire him because she didn't want it to look like a race thing, even though he was horribly unsafe. So, he passes probation. He is still here.
>
> But it got to a point where they kind of—after that DOC was gone, we had a new DOC. We approached her with it, and she kept saying, "Well, yes, I'm going to do something about it." "Oh, that's ridiculous." "Yes, we're going to get him out of here. We're going to get him out of here." And then nothing happened for several months.

> We talked to her again, and she went, “Oh, well, I’ve reviewed the situation. And it seems like he knows what he’s doing. And what he’s capable.” Up until that point, whenever he worked, it was a well-known fact. We all did his job, like we don’t trust him with anything. We set him doing menial tasks—go clean the wheelchairs, get servery set up, all that kind of stuff. **(Jane)**

The frustrating thing that is apparent in this quote is that when it comes to working with someone who is considered not capable of completing tasks in a safe manor, care aides must take care of both their residents as well as the liable care aide. They must ensure that the person is given tasks outside the domain of the residents’ personal care and is kept away from the residents to ensure their safety. This increased workload added to an already heavy workload is itself a liability and compromises the safety of both residents and staff. It places the care aide in a no-win situation, as noted in the field note below:

> [A care aide] told me that it’s so frustrating working with bad [care aides] because there are two options: (1) enable the bad worker and cover for them by doing their work (helping the resident) or (2) let the residents suffer. **(Field Notes 06.07.16)**

Interestingly, when these field notes were written, the option of “reporting” the problematic care aide was not included because by this point of the study it had already become apparent that care aides believed there was limited value in reporting because of the perceived lack of positive outcomes and increased risks that came from this action. In the following excerpt, Lila, a 52-year-old Caucasian care aide with 15 years of experience in LTRC, shares her upsetting experience witnessing abuse between a care aide and a resident:

> **Lila:** I think my personal belief is I think you just have to get rid of them [bad care aides]. . . . I’ve had a situation in a previous job working in a care home where I had to report somebody for resident abuse that I witnessed. I don’t think it happens [often] because you kind of feel like—care aides, we almost feel like we’re brothers and sisters, so we stick together, right? So it’s a hard thing to do, but then you have—I mean, I had to look at it this way, like if it’s going to happen once, is it going to happen again? This is serious stuff. I mean this is abuse, because it’s so easy to do with demented residents, but I always—I mean, I tell care aides when I orientate them, “You have to enter their world, because they can’t enter ours.”
>
> **Researcher:** Yes. Can you tell me about the situation?

> **Lila:** [It] wasn't here. And I was working. I was on the floor. The care aide was in the room with the resident. And I could just hear loud, loud back and forth yelling so I walked in. And when I walked in, the resident was on the toilet. The care aide was bent down in front of her and the resident hit her, so she hit her back. And I said, "What are you doing?" And she said, "Well, she hit me," and I said, "But you can't hit them back." Of course, they hit you. I've been hit lots. But I would never even consider it. I mean, that's where it comes in. You have to walk away. I mean, first and foremost, your resident has to be safe, but you have to walk away. That's where that if you don't insist, they can't resist.
>
> I mean, you have to look at how important is it. Is it that important? Nobody died because they stayed in pyjamas all day or something. They just don't . . . And all you have to do is let your nurse know. I mean, obviously we like people to be dressed and family members don't want to come in and see them in their pyjamas, but, I mean, if it's going to cause a war, you've got to do what's best for them.
>
> And it took me a couple of days [to report]. I didn't do it right away. I mean, I didn't think about what I was going to do. And then I went to my boss . . . That person was suspended. I mean, they didn't lose their job, but they were suspended. We had to work together after and it was very . . . She was mad at me. And it was about, "I lost money. I lost wages." I said, "Yes, but you abused the resident."
>
> **Researcher:** Do you know anyone else who's done that?
>
> **Lila:** No. And I don't even tell people that.

Later in the interview, Lila shared that she felt *"guilty"* and *"lost sleep"* over this whole incident and that is was incredibly difficult for her. She said she does not know of anyone else who has ever reported a care aide abusing a resident in LTRC. It was apparent how isolating and upsetting this experience was for Lila. And to go through it alone, afraid to share her story because of the stigmatization of being a whistle-blower. At the end of this story, Lila said that the way she thinks this situation could be made better is by care aides and other members in LTRC *"communicating, talking about it."* A discussion on the perceived value and risks associated with care aides reporting fellow care aides will be discussed in detail in Chapter 7. Also important is how Lila highlights that care aides are *"like brothers and sisters."* As a team, care aides reported often being very close to one another.

The final behaviors that participants identified as difficult to work with is when individuals either no longer have the motivation to give good care or did not yet have the experience in the role and with the residents to do so. They represent the same problem on opposite sides of the experience spectrum. Individuals who behave as though they are burned out are reported to have *"limited patience"* with their residents, have a *"poor attitude,"* and are apparently *"not interested"* in delivering exceptional care. As one participant articulated, *"I think some people that have been in it for a very long time . . . they've kind of fallen out of love, well, with their job . . . they're just generally not in a very good mood all the time. And they're just kind of burned . . . really burned out."* For whatever reason, care aides who appear burned out continue to work as a care aide in a job they apparently have no affection for. Some reasons participants believed *burnouts* continue to work as care aides is that they have been *"doing it for so long"* and "*they do not know what else to do,"* or that they are close to the age for *"retiring"* due to financial constraints.

Participants reported that they believed the age of care aides may be associated with *burnouts*: *"age is huge, I think . . . as [care aides] age they . . . get creaks and cracks, and aches and pains, so do their personalities."* These care aides have worked in this occupation for enough time and although they may wish to give better care, they were physically not as fit as they once were, which was reflected in their ability to deliver care. Participants reported that working with those who were *burned out* often felt like working with those who were simply lazy (or sluggish), yet there appears to be a different level of empathy and understanding for the behavior. Specifically, they might not enjoy working with these individuals due to their negative attitude and lack of effort, yet there is a sense of respect and appreciation for the service and time they have put in. Perhaps care aides see their own future reflected in these exhausted *burnouts?*

At the other end of the spectrum are care aides with limited experience, either new care aides or casual care aides. Casuals are care aides who do not have a permanent position at Green Lodge and instead are on call to either cover an individual shift or a temporary, repeating shift. Either way, both casual care aides and new care aides have limited experience with the residents at Green Lodge. Some participants reported *"hating"* working with *"greenies"* because it meant a heavier workload for themselves, but others discussed empathy for the role of the causal care aide since although they are less helpful than a regular care aide, casuals and new care aides may end up working harder. While the regular care aides are familiar with the specifics of their residents' care plans and personalities, the new care aides are not aware of this, making the workload heavier and less straightforward to accomplish. Most participants also reported understanding the importance of helping to train new care aides and get casual care aides oriented to their new residents and their care needs.

> They're just trying to help, like, let them know, like, this is what needs to be done for this certain person, but—like today, like, there's a casual on another wing and the full-time person who works there all the time, and she's like, "I'm not trying to be mean, like, I'm just trying to, like, let you know," like it would suck being a casual again, like, because you don't know. Like, you're thrown from wing to wing. **(Linda)**

It is apparent that although Linda recognized that working with *greenies* often translates into a heavier workload for themselves, it is not an easy role being new and that the more experienced care aides try to do their best to orient these new staff members to the residents and flow of Green Lodge. The previous section outlined the different types of relationships care aides have identified regarding the most difficult type of care aides they work alongside. The section that follows will now describe characteristics of fellow care aides who participants reported being beneficial to work with.

The notion of the importance of teamwork was emphasized repeatedly during interviews. It is apparent that the role of care aiding in LTRC is not an individual, one-to-one activity, but instead a partnered or group activity. The frustration that participants reiterated regarding working with care aides who make their job more difficult was evident and was exasperated only when they discussed how they felt powerless to do anything to prevent working with these individuals. Participants generated creative ideas concerning how to dispose of care aides they deemed as *"the most difficult"* to work with and how to obtain and retain more of the *"best care aides,"* The following is a quote from a lively participant who entered this career in his mid-forties. He draws on his knowledge from his previous experience as a used cars salesperson to explain how he believes the occupation of care aiding could be improved:

> First thing you have to do is, well, in my opinion, is to look after the people that are doing a good job and get rid of the people that are doing a bad job . . . Cull the care aides, yes, absolutely. Cull the care aides, yes, absolutely. There's, like—and here's an example that I have experienced. The car industry. You can get away with anything. You can talk to customers badly, you can rip them off, you can take their money—you can up sell them on and all kinds of stuff. The one thing you can't get away with in the car industry is having a bad attitude. Yes, and if they catch you talking to your colleagues and you're in a bad day, you keep that

> [expletive] to yourself, because if management catches you going, "Oh, I hate this place," you're out the door before your feet can touch the ground. Because what they say in the car industry is a bad attitude spreads like cancer, right? So, what you need to do is get rid of the bad ones and keep the good ones and then reward the good ones for doing the job well done. If you can start there, then you've got the bull by the horns. **(Jim)**

It is clear from this quote that Jim believed a *"care aide culling"* was needed, but as far as the specifics of who decides who needs to be culled, that is not clear in this excerpt. Further suggestions from participants on how to improve the quality of care aides in LTRC explored the subject of facilitating team building. Participants reported feeling that there was a limited amount of social cohesion and that management needed to be proactive to remedy this.

> [Care aides need] a chance for people to just get away from this building and get into a setting where they can just relax and be themselves. Maybe people talk about what's—you know, they have a safe room where they can talk about the stresses of the job when—I mean, it's really hard when—because I know where they get to unite. There's administration. There's a lot of little—where people just can't—we can't all share together openly for some reason. But I think if we had [care aides] together . . . I think if people could just get away, do a weekend retreat whether doing team building, when we do a deep relaxation. **(Sharon)**

Sharon's idea stems from wanting to see care aides work closer as a team. She believes if there was a venue in which they could come together, outside of the LTRC environment, then social bonding would ensue and thus lead to care aides working closer as a team on their shifts. This notion of wanting social connectedness with their colleagues, outside of the work environment, was not apparent in all interviews, but it was repeated by other participants. Of course, this suggestion from Sharon may not work or be appreciated by all care aides. As one participant elaborated, *"[the care aides I work with] are colleagues. I don't want making friends at work . . . unless I already know them before I came to work here . . . I just really want privacy in life."* In this case, wanting privacy does not mean this participant will not be a team player on the floor. Everyone has their own preference to the level of closeness they would like with their co-workers and this must be respected. Another suggestion that was often brought up by participants was to reward the *"reliable people that are honest, hard workers."* Participants would like to see some way in which their hard work is acknowledged. For example, something as simple as *"reward people for actually turning up for work. I mean, we have a lot of people here* *that never take a sick day, but they don't get rewarded for it."* It is this notion of accountability that is appreciated by other care aides and facilitates good care being delivered to residents; yet, there is nothing put in place to formally recognize and appreciate these hard working, reliable care aides.

5.2.3. Gender Differences

In this study there were 26 female participants and 5 male participants. Participants reported a number of perceived gender differences were reported between male and female care aides. Jennie, a 44-year-old Hispanic care aide with 12 years of experience in LTRC, was in the unique position to assess gender differences between male and female care aides that that her husband was also a care aide at Green Lodge.

> **Jennie:** And I also think, I mean, this is probably going off the topic, but I still think women get the bum steer. . . . Yes, I think women still have a long way to go and I still think in law or whichever they get treated, we still get, like, "Oh, okay, you did something to that woman," all right? "While you're here. Here's your two months. You were bad." . . . I think we should be treated the same as men. Respectful, we are working now, we're in the workforce, so treat us professionally like it should. Same roles, same thing.
>
> **Researcher**: Have you and [your husband] talked about the differences that he experiences as a male and your experience as a female in the same position?
>
> **Jennie**: The only thing I notice the difference is he [her husband, who is also a care aide at Green Lodge] says he totally stays out of the drama, so that's what try to do now. It doesn't affect him. I think I know him. Like, you know, as women, we're like, "Oh, I don't know why she was so bitchy today," whereas he'd come home and go, "Eh, what's your problem? Who cares? Let's do the job." Whereas we internalize it and they're like . . . And then I think that's just women. So I'm learning to go, you know what? Maybe she's had a bit of bad day, maybe she's having something going on in her life, and we all do. . . . We all do. I would prefer a lot of people don't bring it to work because you get tired of it. . . . The nattering and the same old situation. And, like, some people just love that drama in their life. . . . I hate it. . . . We work hard and our job is dangerous sometimes, sometimes. And I definitely think some girls feel like they're on the bottom and—really we're in the front lines.

It is interesting how Jennie re-frames the "bottom of the totem pole" quip that other care aides reiterate. She emphasizes that care aides are not on the bottom—they are in a battle and they are the front line of defense. In this case, however, who are they in a battle with, the residents? Jennie sees the political climate being as it is between the female care aides because of their behaviors and attitudes. Is it possible that her husband, as a male care aide, is actually treated differently than Jennie is at Green Lodge and that it is because of their different experiences that female care aides (such as Jennie) have a more salient exposure to the politics and bullying that take place and therefore are more given to internalizing their experiences? Can it be that her husband is less sensitive to these issues because of his different set of experiences and therefore is less likely to internalize them?

The span of time in the role of care aide is also predicted to be different between genders, as shared by Rob, a 45-year-old care aide with 23 years of experience in LTRC:

> **Researcher**: You are the longest working male care aide I've ever interviewed. Have you noticed the gender change?
>
> **Rob:** No, they [female care aides] last longer, but no. I think in my class, there were six males.
>
> **Researcher:** Do males last longer?
>
> **Rob:** No, I think they change occupations quicker than females, I find.
>
> **Researcher:** Oh, interesting. Why do you think that?
>
> **Rob** That's just in the years that I have been here. I haven't worked with really any of the males that have—They've all branched out to better paying jobs or whatever their reasons are, but they use this as a stepping stone, basically, for getting to a better paying job.

Rob highlights the fact that males may go for a better paying job after care aiding, yet Rob has been in this role for more than two decades. Apparently there are variables at play (other than an increase in pay) that have kept Rob in his role in LTRC.

Another difference care aides reported regarding gender was when it came to large and physically violent or unpredictable residents. In these cases, if there was a male care aide on shift, participants reported that they would often call the male aide for assistance. For instance, Ryan, a 55-year-old Caucasian care aide with 13 years of experience, shares the following:

> We have one gentleman who’s really big and strong. He’s 91. And we have to watch. We have to watch because anything that we do might get a result that we don’t particularly anticipate. And so I was getting, “Ryan, Mr. So and So . . . ” So I go, like, “Hey,” I got him by the hand. And they relay because we’re way there, like [Nonverbal]. Now, I’ll come out, cover, “Hey, Robert,” for instance. **(Ryan)**

The repercussions of continually calling male care aides to assist in these situations are that these care aides may experience burnout or injury quicker than other care aides due to their increased exposure to potentially dangerous interactions and situations with residents. Also, if male care aides are called upon more often for hypothetically dangerous situations, what are female care aides doing to make up for this disparity in care tasks?

This chapter discussed the relationships that care aides reported having with residents. It appeared that although they found some resident behaviors to be difficult, the consensus was that they cared for their residents and the residents were the reason they stay in this job. It may be thought that attempting to teach care aides not to become emotionally attached and to avoid forming relationships with residents is about as effective as telling them to emulate robots—it cannot work. They are humans in a caring profession. Other more progressive methods need to be developed and implemented to help navigate the emotional distress that care aides feel when a resident dies, which will be discussed in further detail in the following chapters of this thesis. This chapter also reviewed actions and behaviors that participants and their fellow care aides express are barriers to care aides delivering good care to residents as well as perceived gender differences at play between the male and female care aides. The following chapter, Part III of the findings, will review care aides reported challenges they experienced within the LTRC setting.

Chapter 6. Findings Part III: The Challenges of Being a Care Aide in Long-Term Residential Care

Part I and Part II of these thesis results have discussed various aspects of the care aides' experiences and perceptions in long-term residential care (LTRC). Part I began a discussion with participants regarding their initial entry from education into the LTRC environment, including conversations pertaining to how care aides view their role and how we believe society perceives them. Part II reviewed the subsequent relationships that develop within LTRC between care aides and residents and care aides among other care aides. This Part III of the results will review some of the challenging experiences of being a care aide, including the physical and emotional cost of this role in LTRC. The first section of Part III will review the most visible negative component of this role—the physical taxation, injury, and fear of injury that care aides experience on the job. The second section of Part III will discuss the emotional toll that participants feel in LTRC.

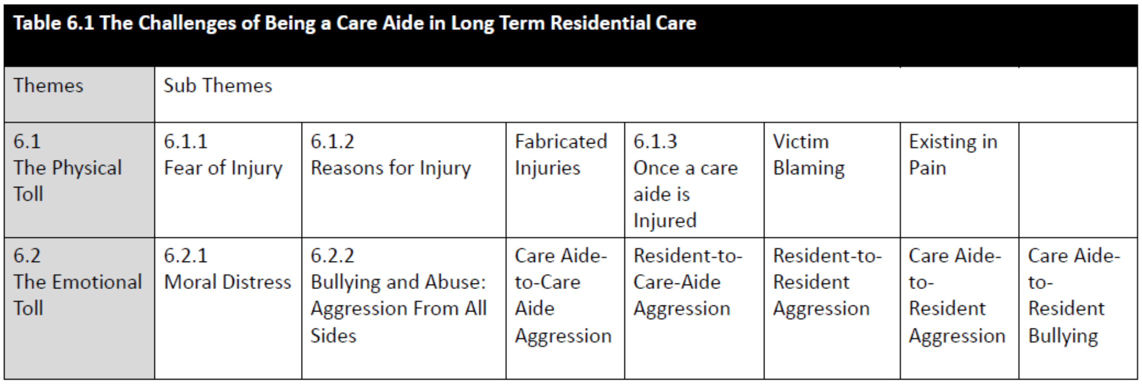


Table 6.1 The Challenges of Being a Care Aide in Long Term Residential Care

Themes	Sub Themes						
6.1 The Physical Toll	6.1.1 Fear of Injury	6.1.2 Reasons for Injury	Fabricated Injuries	6.1.3 Once a care aide is Injured	Victim Blaming	Existing in Pain	
6.2 The Emotional Toll	6.2.1 Moral Distress	6.2.2 Bullying and Abuse: Aggression From All Sides	Care Aide-to-Care Aide Aggression	Resident-to-Care-Aide Aggression	Resident-to-Resident Aggression	Care Aide-to-Resident Aggression	Care Aide-to-Resident Bullying

Table 6.1 The main themes presented and discussed in this chapter. The themes relate to the challenges care aides experience during their role in long-term residential care.

6.1. The Physical Toll

This section will review aspects of the perceived physical cost of being a care aide in LTRC. Although this section is focused on the physical toll of care aiding, it will begin with a discussion of the psychological experience of the chronic *fear of injury* that participants discussed as well as an overview of barriers to facilitating their safety, including appropriate staffing levels and a lack of standardized and continuing education.

A summary of the different types of injuries that participants reported experiencing will also be discussed. This section will end with a review of the reported injuries care aides accrue, as well as a recounting of participants' personal experiences of being injured on the job.

6.1.1. Fear of Injury

There was a consensus among participants that they believe that they have a physically dangerous job, and they reported the fear of injury as a constant reality in their line of work. All participants, except for those who were recently graduated, reported experiencing a role-related physical injury at some point in their career. These injuries are experienced for many reasons, each of which will be discussed in detail in this chapter. Before a discussion of the physical injuries, the fear of injury must first be acknowledged. Almost unanimously, care aides reported a fear of being injured on the job. Heather, a 26-year-old Caucasian care aide with 4 years of experience, shares her story pertaining to being injured on the job:

> I was transferring a resident from her chair off to her bed and I had my . . . Actually, she just needed kind of an assist staff, so I just kind of had my left arm lift under hers. And then we got about three quarters of the way up. She was pushing herself up with her other hand on her wheelchair. And she's one of the more difficult residents. And she's kind of unpredictable when she decided to go right back down her chair. She took my arm with her, sorry. So luckily, I didn't need surgery or anything. . . . I was like "I'm never going to get injured on this job." Because, you see, what these people go off. They get surgeries and they never come back. And you're like, "That's not going to be me." . . . I was so scared I got injured. That was my biggest fear, I think, with this job, yes. **(Heather)**

Heather was open about her fear of being injured when she began her job as a care aide in LTRC. Information taken from field notes recorded after this interview reveal further information pertaining to Heather's situation:

> [Heather] is slowly returning part time to her job after being off for four months due to an injury. She has seen physio four times a week for four months. She also has a two-year-old at home that she is caring for, and she and her husband are thinking of trying for a second child. **(Field Notes 02.09.16)**

It is apparent that although Heather was aware of the risk of being injured on the job and acted judiciously, she still acquired an injury on the job. This excerpt reveals how being injured on the job as a care aide is important for quality of life at home and not just life at work. An injury that occurs in LTRC to a care aide has the potential to negatively affect the care aides' whole family.

6.1.2. Reasons for Injury

Care aides are continually reminded that there is a risk of both injury and violence in their employment. Care aides reported injury being the norm in their role in LTRC, as Ryan, a 55-year-old Caucasian care aide with 13 years of experience, shared:

> We have a lot of injury. People who have been off a long-term injury in lines, so we get casual in, another one, another one, a new one, a new one, another injury. **(Ryan)**

Injuries for care aides occur for many reasons, but the main reasons, as reported by participants, are: (i) discrepancies and changes in the care aides' scope of practice; (ii) working short-staffed; (iii) the wear and tear of the job; (iv) a lack of proper equipment; (v) violence from residents; and (vi) working while distracted.

Participants consistently brought up the topics of workload and staffing ratio as both a barrier to safety as well as barriers to delivering good care to residents. Overall, participants reported believing that their workload has increased over the years due to less staff being on shift, a greater number of residents, and an increase in residents' complex care needs. Sandra, a 55-year-old Caucasian care aide with 27 years of experience, sums up what she believes are the issues preventing her from delivering quality care in a safe manner for both herself and the residents in LTRC:

> The repetitiveness, the scope of it's gotten heavier . . . The complexity of the [residents] is greater . . . staffing hasn't been adjusted, I don't think for the scope of what the [residents] need. The equipment needs for that haven't kept up . . . **(Sandra)**

From the complexities of their residents to the tasks that they are not accountable for, it is apparent that participants feel that their scope of practice has increased and that this leads to more work-related injuries for care aides.

Participants regularly discussed how working without an adequate staff-to-resident ratio was a barrier to delivering good care as well as a facilitator to work-related injuries occurring during care delivery. There were many first-hand accounts that participants shared regarding working short-staffed. As one participant stated, *“for the last rotation I was on, I think we were short three out of my five days.”* It is incredible to think that for most of that participant’s work week she was working at a higher than “normal” capacity due to a shortage of staff. In this way, “normal” capacity can be seen as working short, but this is not what the care aides were prepared for in school, nor is it what they were expecting when they began care aiding in LTRC. The exhaustion and frustration that participants who consistently have to work short experience are heard in the excerpt below:

> Every time they’re short a person, a person gets pulled from their position. So it’s usually the float that gets pulled. So then there is no help in the dining room. So we’re serving food. We’re clearing tables. We’re setting tables and doing dishes. We’re being a waitress and care aide. **(Melissa)**

Melissa highlights the fact that although the care aides were trained and hired for one role—care aiding in LTRC—they have adapted to fulfill other roles in the LTRC setting because of chronically working short-staffed. In this excerpt, Melissa is reporting on how she and her care aide colleagues are now routinely completing the role of dietary aides. Being short-staffed also means less time to deliver care to residents, as Sandra shares:

> When these people [the new company] took over, this is not the company—somehow, the dietaries got cut—their hours—and their duties fell to the care aides . . . Yes, it was like, “How did we fall into that trap?” . . . In the evenings, the ratio is 14 to 1. And there are times when you’re short and it’s not covered . . . And if you’re short and they can’t cover, you are picking up the whole wing. I mean, that has happened, that you’ve been responsible for the heaviest wing, 26 residents. You know? The nurse will try to help you, but she’s also got her job to do too . . . And then, of course, we have the dining room added to our job too. So that takes away from care. It’s care in a different way, but it’s not the physical care. **(Sandra)**

It is apparent that participants believe that adequate staffing levels would facilitate the delivery of good care to their residents and inadequate staffing levels are a barrier to the delivery of good care. This quote also implies that because it is not *"physical care,"* Sandra appears not to see it as in the scope of her role. Importantly, working short-staffed is seen as a risk factor for injury:

> I think it's the nature of the beast, part of it. I think staffing levels and staffing in that would help or if you could do more—if you had more time to do people and maybe pairs, let's say, so, two are going in and doing the transfer all the time. That would eliminate some of [the risk of injury] too, I think. So, yes. **(Heather)**

Heather has an interesting way of describing taking care of her residents as *"time to do people."* Yet, she continues by saying that if appropriate staffing levels were maintained, this may reduce the risk of injuries.

Participants discussed how, due to the very nature of the repetitive and physically demanding nature of the care aide role, injuries occurred because of the routine wear and tear on their bodies in completing tasks. Residents are often unable to move or turn in a way that would make the caring tasks more convenient and safer for care aides and, thus, a large amount of physical strain occurs when residents must be moved.

> [I have been a care aide for] 27 years . . . As long as my body will let me [I will do this] . . . Once I hit the 20-year mark, I started getting injuries. I've had herniated discs. I've got permanent nerve damage in my back from it . . . I've had a broken foot from here. So, yes, it's just . . . [I] just keep coming back. I do love what I do. I've been told to stop. My doctor would love to see me stop, but I just keep going. **(Sandra)**

This notion of *"just keep going"* is an interesting one and is repeated by many participants. Regularly, participants discussed situations in which they personally, or their colleagues, experienced an injury due to a resident moving in a way that was unexpected while the care aide was attempting to deliver personal care. In these incidents, it is possible and often a reality that both the resident and the care aide experience an injury. But from the reports of the participants, it appears that it is more likely that the care aide will risk being injured to prevent their resident from being injured. The main reasons for this appear to be because the care aide does not want to see the resident get injured, so in a split-second decision the care aide moves in a way that will take most of the injury on him- or herself, as seen in the quote below with Jennie, a 44-year-old Hispanic care aide with 12 years of experience:

> I had a lady walking with a walker, and I said a few times, you know, she's—I don't know, but she was walking fine, so, I carried on [trying to move her], and she ended up just letting go and going, "Ah!," and she fell right into me and I went in this way. So I guess it did some damage to my disk and I had to have a—I have an artificial disk now in my neck. [I had] to get surgery because it crushed it and it pinched the nerves and I actually got a leaking of my disk. So, yes, so now I got a disk in there and a plate, a little metal plate, about this big that holds the disk in . . . at night—it's really achy. **(Jennie)**

It makes intuitive sense that the care aides would both report during interviews and experience situations in which they chose their resident's safety over their own. The entire role of care aiding in LTRC is devoted to the safety and well-being of their residents.

Participants shared how their injuries were due to the fact they were working without having access to the appropriate equipment to do the tasks at hand. As one participant explained, she believes that injuries are directly related to not having the appropriate equipment available:

> Some of [the lifts] are ceiling . . . and they'd say it's all two-person lifts, but there's no way we have time to do two-person lifts. So, we're risking the safety of the resident and the safety of us. And it was ongoing. [The other LTRC facility I worked at] was just, like, very, very, very poorly managed place. **(Heather)**

The importance of care aides having access to proper equipment to prevent work-related injuries is important for both the safety and well-being of staff and residents.

Although Part II (Chapter 5) of the results reviewed the often beautiful and compassionate relationships that develop between residents and care aides, acts of violence and aggression from residents toward care aides were routinely discussed during interviews as yet another physical danger related to their role. Violence from residents toward care aides was the least common "serious" form of injury reported, yet participants consistently discussed being aware that this may occur, especially when working with individuals with later-stage dementia.

> You'll get an occasional resident where it's, like, it switches so fast that, like, they don't eat—like, you don't see it coming, right? Like, they're like smiling and happy,

> you know, doing their care. . . . It’s like not quick, right? Most of them, you can tell they’re getting agitated and that you need to come back and try again in a little bit. You circle. You just know not to push, right? . . . It’s not going to end well. **(Heather)**

Although participants reported that violence from residents was not a common form of serious injury, it was a way in which minor injuries were accrued. Most participants shared how they had experienced being hit, bit, kicked, punched, or spat at by residents. Participants shared during interviews how they would dismiss these forms of micro-aggression from residents and not take them personally because they understood the residents had cognitive impairment and were frustrated by something about their current situation or they were in pain and that is how they reacted.

Part of the reason for having the proper equipment and staffing ratios for residents is that without these resources the care aide is liable to be distracted from delivering care safely, which may result in an injury. Care aides, being human, are not infallible machines and as such can be distracted by looming workplace politics or bullying or by working short-staffed or without the proper equipment or trained co-workers. These distractions will use up invaluable space in their mind and may take away from the care aides’ ability to focus. Overtime and with compounding responsibilities and distractions this may lead to care aides being put in situations where an injury is more likely to occur. As one participant reported, *“if your employees aren’t happy, if your employees aren’t focused, if they are distracted by something, then that’s when they get themselves injured.”* It is apparent that the importance of workplace environment and access to resources are entwined with accruing and preventing workplace injuries.

The next section of this chapter will focus on the notion of fabricated injuries among care aides in LTRC.

Fabricated Injuries

On multiple occasions, participants reported being aware of other care aides who purposefully faked an injury to get out of work. This is interesting because it shows how the reality of aging can be used to one’s advantage. As Cynthia, a 33-year-old Filipino care aide with one-year of experience, shared:

> I see lots of people fake their injuries just to get light duties at work or maybe they were injured somewhere, go to work, tell the [Workers' Compensation Board] that they injured themselves at work so that they can get rest, stay in their houses, get paid by the [Workers' Compensation Board]. I'm not going to mention any names because it's not for sure. **(Cynthia)**

Although absolutely *"not for sure,"* participants reiterated how frustrating it was to see other care aides manipulate the system to get out of work. As one participant reported, *"I think people know how to play the system, get what they want. Honestly, people being totally honest, not so much."* The level of deceitfulness felt among fellow care aides regarding their workplace injury claims was visible in interviews with participants. In light of this, the following section will review the sequence of possible events that participants report experiencing post workplace injury when they come back to the LTRC environment and their colleagues may or may not accept that their injury is real, fabricated, or a combination of the two (e.g., a minor injury being exaggerated).

6.1.3. Once a Care Aide Is Injured on the Job

Participants discussed the journey from injury, to time off, to compensation, to healing, to returning to work as a long and tiring expedition. This journey begins with the Workers' Compensation Board (WCB). This information was not surprising given that by their own admission care aides are believed to fake or exaggerate injuries to receive paid time off from work. In light of this, participants reported that it is often a fight on their part to be able to secure adequate compensation for one's work related injury. The tension between the contradictions of faking injuries and actually being injured results in participants reporting spending an enormous amount of time and energy proving that their injury is real. This ordeal may also be compounded by the fact that the care aide may be in pain and not able to work or sustain his or her normal routine or quality of life at home, as Helen, a 44-year-old Caucasian care aide with 8 years of experience, described:

> [WCB] does not support you very well. They just push, push, push. They don't individualize any injuries. They just look at a target as if, "You should be better in this amount of time. . . . Near the end of my claim, I was just an emotional mess because WCB was not being supportive, nor was my employer . . . That they wanted me back to work right away to full duties, which was beyond my capabilities. . . . I had to do, like, a gradual return to work, but . . . the employer

> was reassigning me to compensate for short-staffing instead of focusing on my gradual return to work. **(Helen)**

Even if compensation has been obtained from WCB, it is often not a living wage and it is still a long and bumpy road to recovery. Helen describes how her entire life was negatively affected during the time of her injury. She speaks to how she felt manipulated and pushed back into her role as a care aide even before she had recovered from her injury. Her experience is not an isolated one. Participants routinely discussed feeling pressured to return to work, before they had recovered from work-related injuries. Participants reported that post-injury their experiences were anything but a smooth road to recovery with uninterrupted time off to focus on health and well-being. Instead, participants discussed being harassed by employers to get back to work and judged by co-workers regarding the validity or seriousness of their injury. One participant recounts her story of when she was injured at work and was trying to complete her first day back:

> They'd call me an hour later and tried to get me to stay again. I actually lost my patience once. It was the fourth call I'd gotten when I'd just—it was my second day back after a major back injury. And I actually raised my voice a little bit, which I don't do very often, and told the woman, "I need you to stop calling me so that I can actually do my job because I am now 20 minutes behind because I have to keep answering the phone to talk to you. If you call me one more time, I'm walking out." **(Jane)**

This notion of working while injured was repeated regularly by participants. As another participant recounts, *"[Management] had me working when I was sort of injured."* As was reported by Jane, this participant also felt that she was pushed by management to return to work prior to feeling that she was physically healthy to return to her role of care aiding.

Although care aides are not supposed to be working while injured, there is a program set in place called the *Gradual Return to Work Program* that helps facilitate a smooth transition from returning to work after an injury. After injury, care aides may slowly return to work on this program and are assured shorter hours or a lighter workload. As one participant who was currently on the Gradual Return to Work program explained, *"I am sort of back [after my injury]. I'm doing a gradual return to work . . . I come in three times a week for two hours . . . just to keep in contact with my residents."* This participant emphasized that the reason she is on the Gradual Return to Work program was to keep familiar with her residents. This speaks to the difficulty participants reported earlier regarding being a new or casual care aide and not knowing the residents. Through this program, participants felt that they could slowly get back to work and maintain their knowledge and relationships with their residents. It is clear from the previous excerpt that care aides see the value, both for their residents and for the quality of care that they may deliver to their residents, of keeping in contact with their residents and their needs, even post work-related injury.

Victim Blaming

Some participants reported that injuries and chronic pain are just the *"nature"* of this occupation, while other care aides feel that it is *"up to the care aides"* to ensure that their body is at peak performance level and, thus, if they are injured it is because they are either out of shape or are delivering care in an unsafe manner.

> I would like to see, and maybe this is a personal request, but I would like to see some of the girls have training in how to lift and not exert yourself so much and wear out your muscles so much . . . I don't know what they call it. Just more training so everybody's on the same page. Let's—how can we do this more so that we're not getting injured and wearing out? Because everybody seems to have problems . . . Yes, I mean, in my case a little lady fell into me, so there's not much I could do and I think that for the staff, and maybe this has nothing to do with the managers, but I think the staff should be working out more and doing more weight-training . . . **(Jennie)**

Jennie is a participant who is still on the Gradual Return to Work program. For her position as a post-injury, recovering care aide, it is apparent she is concerned with the overall physical safety and well-being of the care aides and residents. Perhaps without meaning to, Jennie separates herself from other forms of injury that staff may get and puts herself in a completely blameless situation by stating, *"a little lady fell into me . . . there's not much I could do."* Yet, in the same statement, she advises that all other staff members should be working out and weight-training to prevent future injuries. Building on this notion of blaming the injured care aides for their injuries, in field notes taken after interviews there were instances recorded of staff members, including care aides, blaming each other for being injured due to poor care practices on their part. Despite this, most participants who had a work-related injury described how the injury was not due to any fault of their own:

> [Jennie] is currently on a GRW [Gradual Return to Work program]. She said they need overhead ceiling lifts. She said that everyone also needs training in "Muscular Skeletal Injury Prevention." This is training for RCA injury prevention when they are doing manual work. It's used to reduce injury. It is a full day workshop. She sees a huge amount of injuries happen because of just poor practices . . . NOTE: Every RCA that I have seen that is injured says it is not his or her fault. **(Field Notes 03.07.16)**

Although injuries while care aiding in LTRC are apparently a common occurrence, the culture within the LTRC environment is one where injuries do not happen and, if they do, it is because of an error or lack of prevention on the part of the care aide. Unfortunately, the victim blaming does not just stop at the level of care aides. Participants also reported feeling that management too blamed them for the injuries that care aides suffered while on shift:

> Basically, [management] told us everything that was going wrong here was our fault . . . All the injuries that are happening are our fault because we're cutting corners during care. So that's our fault. The whole holiday thing, that's our fault because everybody's always sick. And what else was our fault? Pretty much everything that was going wrong with these places, it was put on us. **(John)**

In this excerpt, John states that management has previously told care aides that everything that is going wrong in LTRC, injuries, sickness, and corner cutting, is completely because of the care aides. It does not matter if management has told this to John because this is what he believes has been told to him. Existing in a culture of blame appears depressing for John and the other participants who have shared their stories. Alongside feeling blamed for workplace injuries and everything else that is negative and occurs in LTRC, care aides with injuries also reported experiencing chronic pain due to their occupation.

Existing in Pain

It was common for participants to report living in chronic pain. Due to previous work-related injury or the constant wear and tear on a care aide's body, caring in chronic pain is a reality for many care aides. As Betty describes,

> **Betty**: I'd say today, a 5 [out of 10 on a pain scale].
>
> **Researcher**: A 5? You know where I would be if I was at 5? I would not be here.

> **Betty**: Oh, well, I know. I probably shouldn't . . . But [residents] suffer in pain all the time . . . So somebody's got to help them."

This quote could be interpreted as representing the altruism and empathy of a care aide regarding her residents. The pain from a work-related injury does not subside when a care aide is off shift, and often care aides reported that this pain may increase when they are at shift or at home, as heard from the following excerpt:

> I was in a lot of pain . . . It wasn't so bad at work. It was more when I stopped moving it at home . . . that it was probably between a 7 and 9 [out of 10]. I was in a lot of pain, and I wouldn't wish the surgery on anyone, because that is just crappy. It is the worst. It is so much freaking pain. I'd rather give birth. **(Patricia)**

It is apparent that the initial injury and subsequent surgical procedures were some of the most painful experiences that this care aide has experienced, even when compared to childbirth. This excerpt from Patricia reveals how the care aide role does not stop once one *"punches out their time card"* and leaves the LTRC setting. The physical consequences that occur can be life-changing and can endure long after the workload and even the occupation has ended. Although the physical toll of care aiding is perceived by participants to be very high, the emotional strain conveyed by participants was often equal to or surpassing the physical pain that they discussed.

The following sections of this chapter will review in detail the emotionally consuming aspect of the role of care aides in LTRC.

6.2. The Emotional Toll

The previous section discussed the physical toll of the care aide occupation, from fear of injury to severe injuries acquired from attempting to complete the assigned care tasks. Building on this theme of challenges while in the care aide role, the following sections of this chapter will review in detail the emotionally consuming aspect of the role of care aides in LTRC, beginning with the moral distress that care aides reported experiencing while in the LTRC setting. Continuing on this theme of the emotional toll, the next section will encompass a review of the micro and macro level of aggressions or bullying and abuses that participants have witnessed in LTRC between both the residents and the levels of the healthcare team.

6.2.1. Moral Distress

Moral distress is stress that occurs when one believes he or she knows the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action. Moral distress is an ever-present reality in the care aide occupation. The following section outlines situations in which participants reported experiencing distressing emotions due to their role in LTRC. Care aides expressed experiencing emotional distress when not being able to deliver the care they would like, and believe they should, to their residents. This feeling of disappointment and regret was expressed even if the reason why they were not able to deliver this care was completely out of their hands. As one participant reported*, "some days, I go home very discouraged and upset because I feel like I haven't been given the opportunity to give my best care."* It is apparent from this quote that this participant realizes that the reason she was not able to do her best job was that she was not set up to do her best job. This inability to deliver the care they want to weighs heavily on participants' shoulders—even after a care aide has left his or her work shift. As discussed in Part II (Chapter 5), care aides develop important and meaningful relationships with their residents. If care aides perceive their residents are being treated in a compassionate way, they may experience less emotional distress and, perhaps, as in the quote above, they would be able to leave their shifts feeling a greater sense of accomplishment and satisfaction with their role in LTRC.

Helpless to Help

Participants expressed frustration at their inability to change the current situation regarding care delivery to their residents. They described wanting to be able to cure the ailments of their residents and make their living situation better. As Sharon, a recently graduated, 38-year-old Caucasian care aide, reported:

> When I can't comfort [the residents] or help calm them, and just have to ride it out, I struggle because I want them to be okay. So if there's something that I just physically or health-wise cannot do, I feel like I'm letting them down. So that usually

> is what makes it hard for me, if I can’t just help that behavior, stop that pain, or stop that confusion. **(Sharon)**

This notion that it is a personal failure on the part of the care aide when these situations arise is repeated throughout the interviews. Even with limited education, resources, and staff power, participants continually reported wanting to do more for their residents. As one participant said about how she views her role *“it’s kind of like sometimes I feel sad about them, like they can’t do what they’ve been doing before. . . . But I’m thinking, I’m here to help them. Yes, help.”* This participant tries to reframe her sadness about the residents’ current situation into an opportunity to help her residents have a better quality of life. In this way, she reframes her negative emotions into positive actions.

Participants would sometimes discuss the emotional stress they felt when they would witness their fellow care aides delivering care that was not, in their opinion, good care. The following is a quote from Cynthia in which she shares how she gets frustrated and discouraged when she sees care delivered inadequately and will take on extra tasks to ensure that, as far as she knows, her residents are well cared for:

> While on the evening shifts, sometimes there would be times that my partner would say, “Oh, this person doesn’t want to go to bed yet.” But I know for sure that that person wouldn’t know what he’s saying sometimes because he’s so confused, especially at the end of the day. Now, when you don’t ask them that, they’ll say, “Do you want to go bed?” Then they say, “No.” So you said, “Okay, it’s time for you to go to bed,” as long as you know that they’ve got everything they needed before they go to bed. . . . And then you just go and do it. Sometimes, she leaves residents behind. And I can’t just go home at the end of my shifts without [putting them to bed], because I don’t feel right going home without me knowing that—oh, with me knowing that they did not even have any care done or anything, because I wouldn’t want to go to my bed myself like that. **(Cynthia)**

Cynthia describes how the perceived laziness or lack of understanding from some care aides she works with will often compound the care that other care aides feel they must deliver to avoid their own emotional distress. Care aides like Cynthia are perceived to be empathetic toward their residents; she would want to be put to bed with her proper evening care having been done and, as such, that is what she tries to do for the residents. Although another way in which this excerpt could be looked at is whether Cynthia is truly being driven by knowledge of the resident’s needs and her own empathy, or if it is her task-oriented nature that is “forcing” the resident to go to bed at a set time? This quote from Cynthia also sheds light on the discrepancies reported between participants regarding what is "good care."

Another cause for emotional distress reported among care aides was seeing their residents experience social isolation and loneliness. Participants discussed having empathy regarding their residents' social situations. They wanted to be able to fulfill all of their residents' needs, including their needs for social interaction. Unfortunately, due to time and staffing restraints, the degree of social interactions they can provide outside of their assigned care tasks is perceived to be scarce. Seeing this need unmet, especially in residents with whom they have strong relationships, leaves the care aides feeling distressed. As one participant describes, *"[I wish I had more] time for [the residents], like gossip and, like, talk if they're—yes, because some of them, like, they were, like, lonely. They need someone to talk to . . . Yes, not most of the time . . . my resident, she wants me to stay more, but I still have other things to do."* Participants recognized that many of their residents do not have family or friends who come and visit them and that most of the social interactions they experience will be with the care aides themselves. As one participant reported,

> So, for me, it's not a particularly favorite person, but it's making sure if that person looks like they need a little connection, then that's what they get. They get the hugging. They get the love. They just get to feel like somebody loves them because they need that. It's one of the biggest things these guys lack. . . . I usually am just more overly compassionate about the people that are in continuous pain or have no family that ever come around . . . We have 96 people. I'd say at least 30 people here don't see family, yes. . . . **(Sharon)**

It is apparent that care aides are aware of which residents experience the most social isolation or pain and do their best to try to alleviate this by working to give them extra attention and affection. As discussed in Chapter 2, an estimated two-thirds of residents have cognitive impairment and express unique and often unmet needs. Participants offered suggestions for how these residents could also receive social support. Unfortunately, due to time and staffing constraints, the care aides' wishes rarely materialize:

> We have a couple of people with dementia, quite a few, who are constantly crying and they want to go home, so it'd be really nice if we can have, like, a little tea party for them or, like, tell stories and jokes. Like, just sit around and dance and

> play music. Like, we do have lots of these groups coming in, but it would be better to have one-on-one. Like, they need one-on-one because they get distracted too easy and they need that comfort, they need a person to talk to. . . . It's just so hard because of the one-on-one, like, we have so many residents, like, it's not enough time for these people. **(Linda)**

It is interesting how Linda laments *"not having enough time for these people."* The sheer weight of this emotional toll that cares aides witness appears to be enough to severely upset and disturb most humans, never mind those who purposefully entered this career because of their innate capacity to be sensitive to the caring needs of others as well as their desire to help people (as discussed in Part I: Chapter 4 of the findings). As one participant put it, *"you know, you're in these people's lives for quite a while. And you see a lot of things. And you can only take so much of it for so long sometimes."* This notion of wanting to help but not having the capacity to do so is a large issue for care aides, which ultimately negatively impacts both residents and staff in LTRC. Although, participants recognized that the emotional distress of not being able to give the best care possible is a subjective experience, and, depending on the person, this feeling will affect care aides differently, as Sandra shares:

> You know, "This person has to go to the bathroom." "That person needs to be fed." You couldn't shave this person. And you know you're not going to get back to do it. It all depends on what your—how your ethics are, I guess because some people accept it and have no problem leaving it like that. Other people don't. I'd see a real difference in how—what we consider acceptable care. I see a difference in that with my co-workers. **(Sandra)**

It is apparent that not everyone will have the same emotional capacity to deal with the reality in LTRC. There appears to be great diversity in the level of emotional intelligence among care aides. As Sandra describes in the previous excerpt, what may weigh heavily on one care aide's conscious may go completely unnoticed by another care aide. Due to many barriers, care aides will not be able to get to all of the tasks that they see need to be done on every shift. Some care aides can accept this reality and others carry the heavy weight of moral distress with them, long after they have left their shift. Another topic related to moral distress that was iterated by care aides was the distress they felt surrounding their exposure to traumatic events in LTRC and their lack of preparation and emotional support during and after these incidents.

Sweeping Trauma under the Rug (Graphic Content)

Nearly all participants had intense stories of trauma that they experienced or bore witness to in LTRC, the frequency and severity of which was dependent on the individual and the amount of experience he or she had within LTRC. Often, the most traumatic experiences that were reported were from the care aides' initial entry into LTRC, which is evidence of their sheer lack of preparedness from their training about the reality of the LTRC setting, as is obvious in the following quote from Jane, a 25-year-old Caucasian care aide with 5 years of experience in LTRC:

> It was our first day in a home to do our practicum. And we were standing at—first hour, actually, because we were standing at the nursing station to get our first report. And I could see just down the hallway a man was being transferred into a wheelchair. And I don't know if the sling was damaged or if it wasn't attached. I don't know. But the sling came loose and he fell. And it just—like a watermelon hitting the floor. It was pretty brutal. The worst part about it for me was watching him, like, grabbing at people, like he was really freaking out. And to me, it's always—I've seen a lot of people die. And I've seen a lot of people die in pain. And for me the worst is when someone dies when they're scared. And that guy was terrified. [It took a couple of minutes] . . . And it was pretty hard to watch. **(Jane)**

Unfortunately for Jane, this experience has seemed not to fade over her years of working as a care aide in LTRC. In this account, she remembers vividly the look on the man's face when he fell and his skull crashed on the floor. She continued on with more details of the story, but the main point is that it was an exceptionally traumatic experience that she now carries with her in her memory. This exposure to "bad deaths" in LTRC is reported to haunt some participants years and even decades after the event occurred. The unspoken fear is, what if they experience this type of death? What if, by accident, the care aides themselves cause or fail to prevent this type of suffering for a resident? What if a care aide who they know is aggressive or neglectful allows this type of horrific death to happen to one of their residents? Care aides are not able to permanently be there and watch over the care that is delivered by other care aides to their residents and, thus, this fear weighs on them, adding to their moral distress. Building on this, the story that follows details two experiences in LTRC that Stephanie, a 55-year-old Caucasian care aide with 2 years of experience, had during her first year as a care aide at a previous facility before she came to Green Lodge:

> I found this guy dead at the bottom of the stairs. I called the nurse and I said, "I think so and so is dead." They're at the bottom of the stairs. The wheelchair's on top of him and he had snapped his neck and died. And then—okay, because there are only two deaths I dealt with in that bloody place. The second one was so and so, a native guy who was like—fuck—always exit-seeking. So he screwed all his windows shut so can open the windows in 24-hour care. Right? So, the psychologist comes and says, "Well, blah-blah-blah-blah-blah." So, the money, the funding wasn't there anymore. That day, they took the 24-hour care away . . . Guess what? The next day, he was walking across the street and got hit and killed by a car. I'm not kidding. I was freaking mortified. He was only, like, 48. I used to sit and paint with him. He was my friend. He was my friend. I did the 24-hour care with him. And they were just, like, "Oh, it is—let it go." They'd just, like . . . One manager quit the next day because he couldn't handle it. He couldn't handle the way the whole thing—the way it was all being processed. They just swept it under the mat, like, "Don't talk. We won't be talking about this." So, one manager was like—he couldn't believe it. He just quit. A lot of people quit after that. **(Stephanie)**

While Stephanie was telling this story, she began to cry and was very upset. Field notes written after that interview further expose the reality of the situation she was experiencing:

> I stayed with Stephanie for a bit longer time than usual, after the recorder was turned off. I gave her my card and told her she can email if she should like to discuss any of these issues further. I also suggested that she talk to her Director of Care, who is terrific and could probably help her gain access to counseling. Stephanie mentioned the fact that she has other trauma in her life. **(Field Notes 02.06.2016)**

This field note excerpt speaks to the fact that, as previously mentioned in Part I of these results, care aides come from low socioeconomic status situations. Because of this, they often do not have the resources or awareness or trust of the medical system to seek formal help with their grief and trauma. Stephanie spoke to having other incidences of trauma in her life, and apparently the compounded trauma felt from her experiences in LTRC as well as from past events in her life was very emotionally distressing for her. In LTRC, care aides are often the first person on the scene when a resident has suffered an injury. It is unfortunate that there appears to be no formal support for care aides to help remedy and work through the traumatic incidences that they are exposed to.

A horrific death is not the only traumatic event that care aides reported witnessing in LRC. Often participants would report not on the naturally occurring end-of-life situations, but also on the sheer trauma caused by witnessing injuries. As one participant stated, *"it's* *not even necessarily the deaths, but just the injuries, the other stuff that can happen."* As Jane recounted during one interview:

> We were doing our checks. And the guy I was working with . . . He spooks easily . . . And he looks in this woman's room. And he comes up, he was, "Oh-oh-oh." And he sort of panicked . . . I went in. And it was literally every single wall. It was—it looks like someone had been killed with a chainsaw in there. It was everywhere, absolutely everywhere. I couldn't believe it . . . Yes. I went in the bathroom. And she was sitting on the toilet. And in front of her was this bloody mound . . . I thought her intestines had come out . . . It turned out that she had some kind of like really, long, ongoing GI bleed somewhere. Her whole body got filled up with blood. And she started vomiting. So it was all over the place. The mound in front of her was all, like, blood clots and stuff that she'd thrown up. She was still throwing it up when we were in there. . . . And it's like, nothing—there is absolutely nothing in any part of your training or education, whatsoever, not even hint. You might find something like that, like absolutely nothing. When the paramedic arrived, I was cleaning the walls, and he actually just went, "Holy shit! You guys weren't kidding." **(Jane)**

This experience that Jane shared sheds light on many issues. First, this event was apparently incredibly graphic. When care aides are exposed to bodily fluids, they must trust that they have been properly informed by management regarding if there are any infectious diseases they may be at risk of acquiring from delivering care. Another participant reported regarding a resident who was being cared for who had an infectious disease: *"We weren't aware of that. And we need to know. We need to know if they've got certain infectious diseases and contagious stuff. We need to know."* Although it seems intuitive that care aides who routinely encounter residents' body fluids would be privy to a potential threat to their own safety, this is not the case. Unfortunately, care aides are aware that they are not always given all of the information of this nature, and it is just one more unspoken safety risk added to their occupation in LTRC.

The frequency and intensity in which participants reported traumatic experiences was both unexpected and distressing. Unfortunately, for some care aides, the situation gets worse and the isolation they reported feeling was only compounded by the fact that society and even their close family members do not comprehend what it is that their job entails. Participants reported feeling alone in their experiences in LTRC, choosing not to discuss their most upsetting work-related events because the general public, even their closest friends and family, may not comprehend the situation and it may cause their loved ones emotional distress to hear their traumatic stories. *"I've had a couple of times where,* *like, someone in my family or one of my friends or something will ask me about, like, 'What's the craziest thing you've ever seen?' . . . Sometimes, I don't actually tell them the real thing because I don't think they can handle it."*

The notion of moral distress and the various aspects in which care aides are exposed to this in their role in LTRC has been discussed in this section. Alongside moral distress, there is the concept of moral residue, which is defined as long-lasting and powerfully integrated into one's thoughts and views of the self. Moral residue comes from moral distress and is thought of as the remaining residue left behind from the distress that was initially felt. The moral residue is perceived to be damaging both to the self and one's career, especially when morally distressing episodes repeat over time. Moral distress and moral residue have long been discussed with respect to the profession of nursing in LTRC. But in comparison to care aides, who, again, deliver the overwhelming majority of direct care to residents, moral distress and moral residue have yet to be highlighted in existing literature. The following section will review two other prominent issues that are reported by participants—bullying and abuse.

6.2.2. Bullying and Abuse: Aggression from All Sides

The previous section discussed some of the violent and traumatic events that participants witnessed. Micro and macro acts of aggression are other issues that care aides face in their role that have nothing to do with the actual care tasks at hand but that contribute dramatically as barriers to completing these tasks. Micro aggression is defined as indirect, subtle, or unintentional discrimination against members of a marginalized group. Macro aggression is defined as everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate negative, hostile, or derogatory messages to target persons based solely upon their position within a marginalized group. Based on the information presented in Part I of these results, the majority of participants interviewed for this thesis expressed feelings that they belong to a marginalized group, due to both their vocation of care aiding in LTRC as well as coming from a low socioeconomic status. Although the participants in this study were predominantly not from an ethnically or racially marginalized group, their position in LTRC and their low socioeconomic status do warrant their belonging to a marginalized group.

For care aides, reported bullying and abuse toward each other, residents, and other staff members was regularly discussed. There is a fine line between bullying and abuse, but both can be uncomfortable, at the very least, as well as some of the most horrific and sometimes even deadly experiences for someone. As one participant reported, *"The drama, the craziness, the bullying—it's bad."* There is an apparent problem with politics, abuse, and bullying within LTRC that participants reported. This section will review the bullying and abuse reported by participants, beginning with a discussion of bullying between care aides, to bullying and abuse from residents to care aides, and ending with a discussion of abuse participants reported having witnessed from care aides toward residents.

Care Aide-to-Care Aide Aggression

The amount of bullying that care aides discussed receiving from other care aides was surprising. Participants unanimously agreed that workplace politics negatively affected the care they were able to deliver. Participants reported being less trusting, positive, and joyful during their role in LTRC because of the negative effects they experienced being on the receiving end of bullying and gossip. As Betty, a 50-year-old Caucasian care aide with 30 years of experience in LTRC, explained:

> [Another care aide] says stuff behind my back. But I always hear about it. You know, it's like . . . it's changed my attitude and it makes me—I don't know. I'm not as—I don't know how to say it. I don't put up with stuff like I used to. So I think it's changed my personality. And I don't like the way it's changed me. **(Betty)**

Other participants reported on the reality that sometimes care aides may be able to deliver good care to their residents and treat them in a respectful manner, but the same may not be true when it came to interactions with fellow care aides. As Cynthia, a recently graduated Filipino care aide, described:

> Sometimes, [care aides] are good with residents, but then they are very bad to their co-workers. That's not good either, because you are not thinking about your co-workers' feelings . . . If your co-worker felt so bad with what you did and then now, it will reflect to the care that [they will] . . . provide. So, I guess, yes, it should be client-centered, but then you're also supposed to be very sensitive with your environment, with your co-workers. And, yes, I observe. So, yes, there's politics and there's power tripping. **(Cynthia)**

There appears to be a cycle of negative repercussions that takes place when a care aide partakes in bullying behaviors. The adverse implications of these actions do not fade into the walls of the LTRC environment, but instead reverberate among the care aides, negatively affecting the whole care ecosystem. These behaviors are perceived to affect the culture of care, negatively affecting care aides self-worth and pushing the limited amount of power back and forth between those grasping for it at the *"bottom end of the totem pole."* Participants reported being aware that bullying was an issue in this setting even prior to receiving employment in LTRC, as Linda described:

> It's so funny, because, like, when I moved here, I was like, "I'm not going to be bullied." And it was funny—but when I got trained, I had, like, an older lady who was, like, kind of grumpy who trained me. She told me, "You're not allowed to wear your watch." And I looked right at her and I was like, "You're telling me to take off my watch? Why don't you take off yours first?" And that was fine . . . and she took it off . . . And so, I earned my respect from her . . . and we're like best friends [now]. **(Linda)**

This excerpt from Linda's interview recounts how she had to defend herself from the comments of a more experienced care aide when she first entered LTRC. She now perceives this more experienced care aide as a friend because she stood up for herself and *"earned"* respect from her. Often participants would describe the sheer amount of gossip between care aides and how it was almost laughable. As one participant described,

> It has been awful . . . As far as little junior high cliques. . . . You get the [small town] girls. You get the [city] girls. You get the—"Yes, oh, I'll invite my friend—I know somebody who needs [a job]"—yes, and then it's always, like—you know we can hear you [laughs]. Oh, it's striking and they don't seem to care . . . it's, like, not the staff room. We used to call it the gossip room. . . . And it's not just the care aides . . . but because it's, like, junior high, right? But it seemed to just ask that and we'll just go—and it's gone on and on like nobody really stopped it even though they don't like it. It just perpetuates more. And it just became a bad habit, I think. **(Betty)**

Interestingly, Betty highlights during this interview that it is not just care aides who partake in this gossiping behavior; the other members of the healthcare team also contribute. It is noted that the one room for care aides devoted to their own well-being and cohesion as a group, a designated space to socialize and relax from their shift work, was labeled as a room where care aides would speak behind each others' backs about their private or personal affairs. Considering this, it was common for care aides to share during the interviews that *"I eat my lunch in my car"* just to avoid the gossip.

Participants believed that bullying and gossip are linked together and to avoid one you must avoid the other. They would often discuss how the only way they found to avoid the gossip and thus the bullying in LTRC was to avoid socializing with the other members of the healthcare team all together. One participant described the measures she would take to stay away from the gossip:

> I don't go to the staff room besides lunch time. When I take other breaks I go to my little chat room, I look at my phone and read my stuff and try not to listen to any of it. Like, if it's there, that you must listen, then, yes, you have no choice but try to walk away as much as you can. That's all you have to do. **(Carolyn)**

In this quote, Carolyn identifies that care aides do have the power to avoid some of the politics that take place in LTRC, but it is apparent that *"walking away"* is not always a viable option for all situations and may even lead to further negative recourses if it is apparent that you are avoiding the gossip taking place. Some participants reported changing their entire working shift and lifestyle to try to avoid the gossip and bullying experienced on certain shifts in LTRC. When conducting interviews on the night shift, participants would often say that they enjoy working *"nightshifts because there is no drama on nightshifts."* The reasons participants reported being the recipient of bullying behaviors from other care aides in LTRC were varied. Often participants would report being bullied simply because they were the new care aide on the floor, as in the case of the previous excerpt from Linda. Sometimes participants would report being bullied for being perceived as working harder than the rest and thus casting a bad light on the work ethic of the other care aides, as in Jane's recounting:

> When I worked evenings, I got made fun of because I'd still be working up until 10:00 p.m. because some of my residents don't want to go to bed until 9:30 p.m. And what's wrong with that? . . . [The other care aides] would have everybody in bed by 8:00 and then they'd sit at the nurses' station playing on their phones and make fun of me for still working . . . But for me, if one—this old lady wants to sit there for five minutes and wash her face because she spent her whole life washing her face for five minutes before bed, I'm going to stand there and let her do it. There's no reason why I shouldn't. **(Jane)**

It appears there is a mentality among the care aides that anyone who goes against the status quo of the majority is a risk to their established work routines. The fact that Jane highlights how the care aides sit at the *"nurses' station playing on their phones"* is revealing to the reality of their job, that, on certain shifts, there is time to sit and play on the phone and not constantly *“run off their feet”* as other care aides shared. The concerning thing is that cellphones all have cameras on them and cameras can be used to take pictures of residents, infringing on their right to privacy.

Care aides reported that racism was also seen in LTRC. In the following passage, Karen, a 35-year-old Caucasian care aide with 8 years of experience in LTRC, explained how the previous LTRC facility where she was employed had mostly Filipino care aides and very few Caucasian women. As described in Part II of these results, the ethnic diversity seen in the previous facility where Carrie worked is more aligned with the majority of LTRC settings in North America. She described a situation in which she perceived having experienced racism:

> I felt bad with the [new] staff that came in . . . because we’d always do this poll. Like, honestly, with the Caucasian staff, we do this poll about how long they’re going to last. Because they’d come in and then it was like initiation. It was like you’ve got initiated when you come into the building. . . . [The Filipino care aides] always talk behind your back. And then they’d always be talking in Filipino and then you hear your name, but then they continue talking in Filipino. So you’d know that they were saying something about you because you heard your name. **(Karen)**

It is apparent that Carrie felt morally distressed at how the new Caucasian care aides were treated, but she believed she was powerless to change it and thus participated in it. On the same theme, one Filipino care aide shared some of the difficulties in being on the receiving side of bullying from other care aides due to her limited English language skills. Carolyn had 4 years of experience working as a care aide in LTRC and described one of the most difficult experiences she has had dealing with a bully while working in this setting:

> Actually, there was a couple of people. One person, because she’s picking on me. She was just . . . [bullying]. But she’s done—I think. She was making fun of my English . . . I think [it’s] just her personality. She like to make fun of people . . . I [am] very happy I don’t have to [work with her] anymore . . . The bully does it though. She’ll pick on one person, and then I have no effect ‘cause I do cry when I get home . . . She like to get into you, so you become close friends. So you share things with her, and then she start to use those things against you. And then make fun of you in front of people . . . There’s a few people who stick up for me. **(Carolyn)**

This apparent game of manipulation, coercion, and humiliation that Carolyn described being subjected to by another care aide is disturbing. A few times during this conversation, Carolyn repeated how happy she was that she did not *"have to work with this person anymore."* Thankfully, Carolyn did feel that there were other staff members who stood up for her during this experience, yet it is unclear why this type of "hazing" had to occur in the first place.

As discussed in Chapter 2, there is no lack of care aide positions, nor are their opportunities for care aides to be promoted or move up or down in rank. There does not appear to be a viable reason to make another person feel poorly and embarrassed, unless the reason for this type of malicious behavior is purely due to a lack of respect and a need to exercise one's limited power by demeaning another person who is new and visibly different from the majority. Bullying and gossip are not only between care aides. Participants also reported various other ways in which they say the politics in LTRC negatively affect them as well as their residents, including: (i) bullying from residents to care aides; (ii) bullying between residents to residents; and (iii) bullying from care aides to residents.

Resident-to-Care Aide Aggression

Some participants were adamant that they experienced bullying from some of their residents. Residents in LTRC are a varied group of individuals who have multiple physical and cognitive ailments. It is unclear whether this is bullying behavior or behavioral symptoms of dementia; regardless, participants reported viewing it as a personal attack that was not disease related. As one care aide with 3 years of experience described,

> It really does happen. And I think it happens more often than people realize, because they always talk about resident abuse, but it's never about care aide abuse—the abuse that we take from the residents. And there's a lot of it. . . . I've been punched, kicked, pinched. . . . A lady that I was changing, you know, you just go in and you change her. She'll spit at you, she'll kick you, and she'll pinch you . . . Every time, that's just how she is. I don't know if that's her sign of pain, but that's what she does. . . . [She also calls us] stupid. "You're stupid, you're useless." **(Corinna)**

Corinna shares that she finds it frustrating that there is so much emphasis on protecting residents from abuse from care aides whereas she feels that she is regularly abused by residents. It is interesting how Corrina has chosen to take this situation personally, though, and not blame the symptoms of dementia or the LTRC environment in which this resident has been placed.

Participants did report understanding that sometimes dementia changes the residents' behavior and that often because of this it is not their fault. For example, one participant reported, *"You also have to realize with the dementia residents too that they're not responsible for their behavior. It's the disease, right? So, if they're rude or something, you don't take it personally. You have to realize that this person's brain isn't functioning properly."* Although this was a common point of discussion during interviews regarding upsetting behaviors that their residents portrayed, it still did not alleviate the frustration and pain that care aides felt when these occurrences would take place. Participants did speak to being proactive in these situations and changing their behavior when they are aware a resident has dementia. They emphasized that one cannot use the same care and communication approaches for residents with and without dementia. As Helen, a 44-year-old Caucasian care aide with 8 years of experience in LTRC, describes,

> You also have to realize with the dementia residents too that they're not responsible for their behavior. It's the disease, right? So if they're rude or something, you don't take it personally. You have to realize that this person's brain isn't functioning properly . . . And try to find a way around it to distract them, to get them focused on something else. You need to be usually a lot quieter with these people, a more gentle approach, a very gentle—let them know what you're doing, and very—not too much talking, because what I learned at one seminar was that a lot of dementia residents actually only hear every third word you say . . . So if you're, like, "Okay, come on. Let's get up. We're going to go into the bathroom. We're going to this and that and that," like, they are not taking it all in, you are confusing them. So you just kind of need to be very specific with your directions to them. **(Helen)**

In this quote, this participant speaks to some of the differences in the care she practices with a resident with dementia. She emphasizes that the care aides' communication must be tailored to the individual needs of the person who has dementia. An important point that relates to Part I of these results is that Helen felt she needed to supplement her own care aide education to bolster her understanding of good dementia care. It is unclear if she participated in this seminar because she felt she needed to have stronger dementia care skills or if she wanted to know how best to prevent and protect herself from possible violent situations, or a combination of the two. Helen continues by discussing what she perceives other care aides do wrong when delivering care to someone who has dementia:

> A lot of people don’t take [dementia] into consideration. They try to provide care the same way to every person, every resident they go into. But you need to really individualize to meet their needs . . . Even your facial expression will affect them. If you go in looking frustrated, they’ll mimic you a lot of the times. You’ll notice if you’re having a bad day and you’re feeling—and you don’t go in with your nice smile on your face and everything, maybe the tone of your voice may be a little different because you’re frustrated, you can tell. A lot of times, they’ll mimic. **(Helen)**

In this excerpt, Helen stresses the importance of the care aide’s attitude when delivering care to residents who are living with dementia. She highlights the importance of care aides delivering individualized care to their residents. Most participants had numerous stories regarding being abused by residents, and it was impossible to separate what were symptoms of dementia from what were bullying or abusive behaviors on the part of residents toward the care aides. Participants also shared stories of residents abusing other residents.

Resident-to-Resident Aggression

Participants reported witnessing acts of minor aggression and abuse among residents. These incidences vary from bullying to acts of violence. As one participant described, *“I mean, residents get murdered [by other residents] sometimes.”* Another participant recounted a story she heard that has affected how she perceives her role in LTRC. She could not, however, say if it was true or not. She worked on night shift and was asked why she felt she had to do so many checks that she previously called useless and *“a big waste of my time.”* Her response was that she heard that *“a resident beat on another resident for a long time. And nobody knew. And the resident died.”* And it is because of this story that she continues to do her routine checks on night shift. Still, another participant on day shift, Patricia, a 42-year-old Caucasian care aide with 10 years of experience, describes the more common forms of abuse and bullying seen among residents:

> Usually [residents bullying another resident looks like] yelling and they’ll yell and scream at each other or they’ll ram their chair into the other person’s . . . I don’t think [the residents with dementia] realize they’re doing it, but they get so pissed

> off because they're trying to get through and this one wheelchair—this one person maybe can't move their wheelchair, so they're ramming and then the yelling and screaming starts because they can't get through. **(Patricia)**

Patricia viewed abuse and bullying among residents as often coming from residents being unaware of what they are doing and, in this way, it was ignorant and perhaps innocent behavior. This is not saying that these behaviors are not inevitably harmful to other residents; her suspicion is that the resident at fault merely does not have the cognitive capacity to know what his or her behaviors are. In other cases, it appears that the residents are aware of the distress they are causing other residents, and that it is to assert their power and dominance over the resident, as in the excerpt below from Judith, a 38-year-old Caucasian care aide with 8 years of experience:

> I've seen [this] more than a few times . . . [We had] this quite large resident who is in a wheelchair. And he is in a privately-funded room, and then due to whatever happened—paperwork, not being filled out—they had to put him in a non-funded room. So he had to start at the beginning and go back to a two-person room like everybody does when they're admitted here. And for some reason, he had the sweetest, little Scottish roommate. He hated him, told me he was going to kill him, told him he had [a knife] in the Chevy, in his trunk, [and] he was going to go get it. And he would literally try to attack this poor little guy. You know, and it was known about, and we'd have to diffuse the situation. **(Judith)**

In this situation, it appears that every character involved suffered. The *"larger"* resident was put in a cohabitating situation with a stranger. He clearly was not comfortable or happy with this living arrangement and reacted in a violent manner in an attempt to change it. The other *"little Scottish"* resident was also a victim of this circumstance. One can only imagine the horror this new resident felt, having moved into a completely new institutional living arrangement and sharing his quarters with an overtly aggressive, harassing, and much larger resident. There was also concern on the part of the care aide in attempting to diffuse this situation but still leaving every shift and wondering if violence would occur on the next shift and if both residents would be safe from harm.

Unfortunately, bullying and abuse among care aides, from residents to care aides, and among residents is not the only maltreatment that is witnessed in LTRC. Often participants would speak to the abuse they would see other care aides inflict on residents.

Care Aide-to-Resident Bullying

Care aides reported witnessing and being aware of abuse and bullying from care aides toward residents. There were various forms of mistreatment on the part of care aides toward residents that were described by participants. Sometimes participants would not know if what they had viewed was technically bullying, but they knew it was mistreatment nonetheless. For example, Helen described something she has labelled as *"purposely agitating":*

> I have one resident in particular that I would consider is almost bullied . . . A lot of care aides have the preconceived notion that she's bossy, that she's rude, that me, as a care aide, that I am catering to her. I'm not catering—I'm meeting her needs. For example, if she wants her left sock put on before her right sock, I am more than willing to do it because that's how she wants her care done. And she is mentally able to tell me that, as a care aide. Maybe some of them are used to putting their right sock on before the left sock. So, to them, "Well, no, it doesn't matter. I'm putting your—I'm putting this sock." So, what they will do is they will agitate . . . because she'll ask you to do things specifically in a specific order. And they'll argue. They'll start an argument with her and will escalate her agitation to the point where she's frustrated. And the care aide's frustrated. **(Helen)**

It is apparent that it upsets Helen the way she sees other care aides treat this resident. She sees some of her fellow care aides as collectively and purposely agitating this resident. She also sees how they perceive her as *"catering"* to this resident, whereas Helen believes she is merely trying to care for her. She states that care aides will argue with this resident regarding the details of her care delivery, to the point where both the resident and the care aide are frustrated. This appeared to be a common theme reported among participants, that if they provide a high level of care, higher than the average care given by the rest of the staff, then they are bullied for doing so, as was seen in the previous situation described by Jane, who worked on the night shift and let her residents stay up later if that was what they wanted. Helen continued by saying:

> When it's my last shift before I go to the other wing, she'll be like, "Oh, it's your last day today. Ah! Oh! What am I going to do?" So that makes me wonder, what are these other people doing? And another thing that happens with her is when she rings her call bell. People think she's just doing it to be annoying and rude. And they will purposely ignore her call bell, "Oh, she's ringing again. Oh, she can wait." I hear that constantly. "She can wait. She can wait. She can wait." Just—do you know what I mean? Because it's like, they're trying to—like, there's like a . . . there's

> a fight for control because they think, “Oh, she’s just ringing to make me mad, to make my day horrible.” **(Helen)**

Helen describes how she is concerned about the quality and quantity of care this resident receives when she is not on shift. She describes a *“fight for control”* between certain care aides and this resident. In the previous passage, Helen described how this resident is sometimes *“purposefully agitated”* by care aides regarding the specifics of her care delivery. In this excerpt, Helen continues by saying she regularly witnesses care aides ignore the call *“bell”* when this resident would call for help and say that she can wait. Helen reported being in disbelief that care aides, who are trained and employed to care for residents, would choose to engage in an argument with a resident, neglect care requests, and purposely agitate them merely to exert their own limited power.

Although purposely agitating and neglecting residents are horrible forms of abuse, they are not the only examples reported by participants. Sometimes participants would discuss incidences when they would see physical abuse from care aides toward residents, as Corinna described:

> [This care aide is] a bully when it comes to residents . . . this one writes on a resident, as she’s got a mark or something. She writes on them . . . If you got a bruise, she’ll circle it. Like, you don’t write on people. She’s rough with them. She doesn’t talk politely to them . . . There’s some funky stuff that goes on here . . . And then when you talk to her about it, she’s like, “My mom’s worked in a group’s home. My mom knows how to deal with people.” . . . And it’s been brought up . . . They’ve been dealt with, yes. Supposedly she’s leaving and going somewhere else . . . Unfortunately, that [other] facility is going to get stuck with her. **(Corinna)**

From this excerpt, it is apparent that Corinna is disgusted by the behavior of this care aide, whom she believes is abusive toward residents. She described how she is happy that this care aide is leaving Green Lodge because she perceives the care aide as showing such abysmal and disrespectful behavior toward residents. This quote also speaks to the “circle of violence” often seen in LTRC. Care aides, who have been found to act dangerously and abusively toward residents, are perceived by participants to be almost impossible to fire without being hired again by another facility. As previously discussed in Part II of these results, participants often reported that they believed that the union was responsible for protecting bad care aides.

Another form of abuse that was reported by participants was psychological abuse from care aides toward residents. Psychological abuse is characterized by a person subjecting, or exposing, another person to behavior that may result in psychological trauma. As previously discussed, residents in LTRC often have various forms and levels of severity of cognitive impairment, including, but not limited to, dementia. Because of this, what may not seem "real" to others, may, in fact, be very real to a resident with dementia. For instance:

> We had a lady [with dementia] who never slept at night . . . She had a little stuffed dog that she thought was real . . . It was her dog and had a name . . . she was very attached to it. It was one of the only ways I could get her to go to bed, was to make sure she had this dog. And one time, she was yelling in the dining room because she was scared and she was stressed out. We'd just come on shift so she'd been with the evening staff, which she was always stressed out when we first came on shift until we could talk to her and calm her down. [This care aide] went up to her and he's standing over her, all intimidating, and basically telling her to keep quiet. And she starts yelling at him and telling him to go away. So he grabbed the dog and went to give it to her. And she sort of snatched the dog off of him. And she's like, "You get away from me." And he was mad that she was still yelling at him. So he snatched the dog out of her arms, lifted it up, and slammed it down the ground as hard as he could. She burst into tears because she thought he'd killed her dog. **(Jane)**

The role of animals, or in this instance a toy animal, in mediating relationships is often an invaluable source of comfort and security to residents in LTRC. In this quote, Jane describes how a certain resident with dementia was easier to care for if she had her toy dog with her, to relax and calm her. Another care aide apparently used the attachment that she had with this toy dog to punish her when she was not behaving in a way that was appropriate to him. In this story, it appears that both the resident and Jane were distraught; the resident felt that her dog had been murdered in front of her, and Jane was in disbelief that another care aide could act so maliciously towards a resident.

Abuse and bullying are not limited to the two main characters in LTRC, residents and care aides. Sometimes participants would report witnessing abuse from family members toward other residents as well as the care aides. In the following incident, Patricia recounts being violently attacked by a family member of a resident:

> [The resident's wife] was physically abusive . . . to him and to the [other] residents . . . and to the care staff. She punched me in the back . . . She thought that he was

> having an affair with everybody . . . She was escorted out . . . she had dementia . . . and is in another facility, in a locked-down unit now . . . [She was] very jealous. . . . The care staff—they used to have to sneak [her husband/the resident] to go have a bath and she would bang on the bathroom door . . . Yes, she was nasty . . . she attacked a few of the care aides. One time, she thought I had taken him on the elevator and I hadn't. He's in the bath. . . . I'm like, "Sorry, Olive. I have no idea where he is right now," and I went to walk away and she raced after me and punched me right in the back as I walked away. I'm like, "Are you kidding me?" And I think she scratched somebody else, like ripped apart one of the care aide's arms . . . Tiny, aggressive woman . . . I just reported it. There's not really much you can do . . . I mean, it hurt for a couple of minutes, but then I was fine. Like she didn't really have that much strength. **(Patricia)**

It is apparent that in some cases care aides understand and label residents' actions as part of the symptoms of their dementia, while in other incidences this seems not to be the case. Patricia details her account of being hit by a family member of a resident and how this family member was also known for acting violently toward other residents, the care staff, and her husband as well. She also speaks to care aides having to modify the care they deliver to residents to avoid abuse or outbursts by agitated residents or, in this case, their family members. Patricia also speaks to the fact that when care aides are abused in their role in LTRC, there is very little they can do to ensure that the incident will not happen again.

Beyond these cases of physical abuse, purposefully agitating, psychological abuse, and neglect, there are also allegations of sexual abuse that occur among care aides and residents.

> A resident . . . said, "I don't want her to care for me anymore. She stuck a finger in my bum." . . . and she'll make completely inappropriate comments while doing care on the male in front of another care aide. And it didn't get recorded right away. It got told from another care aide. And this person trusted me. And I think that people know now if they come to me or something. If they're not going to do something about it, I will. So, I make sure the appropriate people knew about it because it took so long. And there was no specific date and time written down. There was nothing that could be done about it. So eventually, this person was made to drop their line and they weren't going to be given a line again. And they went their own way. But after two separate incidents, this person continued to work on the floor for another three or four months. It made me sick to my stomach every time I see her on the floor. **(Judith)**

The frustration that Judith recounts is evident in this passage. She wants something to be done to prevent this abuse from happening and she states that it makes her physically *“sick”* every time she sees this care aide interact with residents, but she feels that there is nothing that can be done. It is also evident in this excerpt that Judith views herself as reliable and trustworthy, that she is willing to put in the time and energy to ensure the safety of her residents.

In nearly every interview participants brought up residents with dementia. The following is an excerpt from Karen, a 47-year-old Caucasian care aide with 9 years of experience in LTRC. Karen describes Betty, a female resident with dementia:

> I’ve never and you probably would never meet anybody like her either. She is off her rocker—that lady. And she drives everybody nuts because she has no short-term memory. So she will come out of her room 20 times in 20 minutes to ask when her lunch is coming. And we’ll get all anxious and upset. And she’s all worked up and huffing and puffing and her anxiety level is through the roof because she wants to know when she’s getting her lunch. And she'll ask everybody, every single person. I had—I said to Ruth. The other day, I said, “Betty, when you ask a question, do you listen to the answer?” And she actually, she said, “Most times,” which I thought was kind of funny.
>
> And I said, “Okay, then listen to the answer now. Lunch will be out in five minutes,” because it was five [minutes] to 12:00. And as soon as I walked away, turned my back, she asked the next person that came in right behind me probably 10 seconds later the same question, “When am I getting my lunch?” So she can drive a lot of us pretty crazy. . . . She does have a little bit of medical background, which makes it a little bit more frustrating for us because she already knows what the deal is when it comes to care so . . . she would—she resists.
>
> She’s done it herself even when you take off her underwear and show her how nasty they are. “That didn’t happen. I’ve already washed myself” [I asked,] “Did you put these back on?” “Oh, of course I didn’t.” “Well, then how did [it] get on your bum?” “Well, I don’t know,” and that’s what it’s like. . . . She’s so very demented but she has an excuse for everything . . . So, yes, it’s like that. And most times, she refuses. And I know that [other care aides] probably don’t try that hard. And I wouldn’t blame them . . . I mean, having to bathe her, you’re mentally drained. You need to go have a nap because she’s just worn you right down . . . But then, there’s other times that I bathe her. And if I try and make, lighten up a few things, I’ll actually get her joking and laughing . . . Like, she’ll say, “Oh, my bum is wet, and I’m like, “Well, I can’t dry your bum, Betty. You’re sitting on it.” “Oh, [laughs].” . . . So it just—it depends . . . I just don’t take no for an answer. I just start rummaging through her drawers and grab her underwear and her clean night gown because she’s going to go right back to bed. And I will take the covers off. And I will grab her feet and swing her out of bed. And if I have to, I told her, “You smell. You stink.” “How do you know it?” I said, “Well, everybody is telling me that they can’t come in here because you smell.” . . . I don’t treat them any differently than I do anybody else. **(Karen)**

One of the many points of concern from this excerpt of Karen's interview is when she states that she physically abuses Betty (*"I will grab her feet and swing her out of bed"*). Yet, Karen does not view this behavior as abuse. In fact, it appeared to be a point of pride when Karen asserted that she does not treat the residents *"any differently"* than she does anyone else. The issue is that Betty and the other residents are not "anybody else" with whom Karen may interact outside of her role in LTRC. Betty has dementia and as such needs to be treated in a way that respects her unique needs.

At the end of the interview, Karen and I discussed what types of education would be helpful for care aides. I mentioned a dementia workshop that was taking place at Green Lodge, and she said: *"I am not going . . . I've been to too many dementia workshops. And I'm pretty good with dementia."* Apparently Karen believes she is good at delivering care to residents with dementia, but her fellow care aides may disagree with her rough care routines.

Conclusion

Part III of the results presented some of the challenging experiences of being a care aide, including the physical and emotional cost of this role in LTRC. The first portion of Part III reviewed the most visible negative component of this role—the physical taxation, injury, and fear of injury that care aides experience on the job. The second section of Part III discussed the emotional toll that participants experience as part of their role in LTRC. The overarching topics that negatively affected the participants' emotional well-being were feelings of helplessness regarding being unable to meet all of the needs of their residents, workplace bullying, lack of support for traumatic incidences, and aggression (care aide to care aide, resident to care aide, resident to resident, and care aide to resident).

The next and final chapter of these results, Chapter 7, Part IV of the findings, will focus on the topics of power and institutionalization and how these are presented among the care aide role in LTRC.

Chapter 7. Findings Part IV: Perceptions of Power in Long-Term Residential Care

The preceding three parts of the thesis findings discussed the care aides' entry and current state in LTRC. Part I reviewed participants' initial exposure to the care aide occupation, their experience in education, and the shocking reality of their role in LTRC once employed. Part II discussed the relationships care aides reported having with residents as well as some of the supportive and disruptive behaviors that other members of the care aide team present in LTRC. Part III of these results discussed the physical and emotional toll that participants reported experiencing as care aides in LTRC.

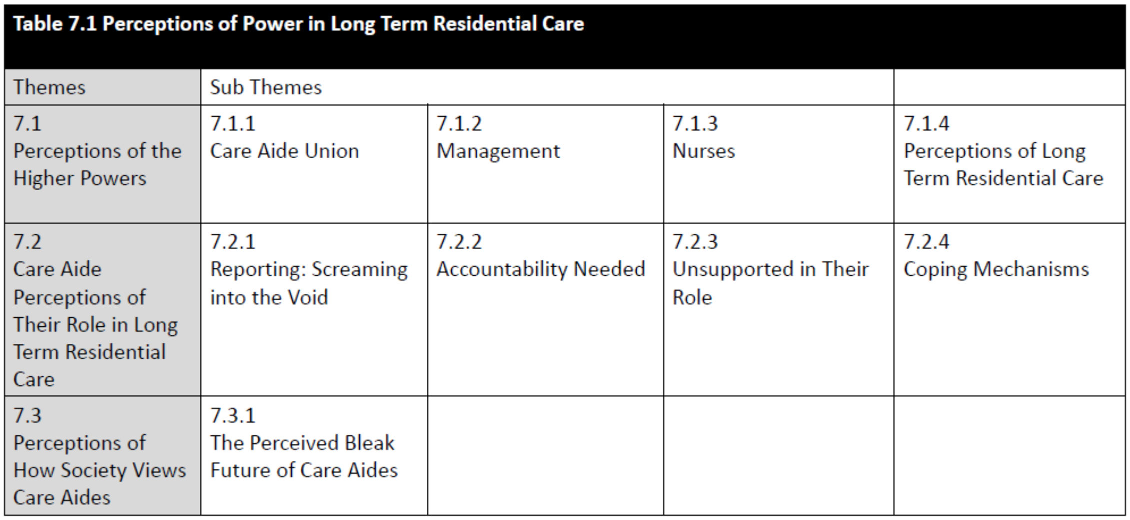


Table 7.1 Perceptions of Power in Long Term Residential Care

Themes	Sub Themes			
7.1 Perceptions of the Higher Powers	7.1.1 Care Aide Union	7.1.2 Management	7.1.3 Nurses	7.1.4 Perceptions of Long Term Residential Care
7.2 Care Aide Perceptions of Their Role in Long Term Residential Care	7.2.1 Reporting: Screaming into the Void	7.2.2 Accountability Needed	7.2.3 Unsupported in Their Role	7.2.4 Coping Mechanisms
7.3 Perceptions of How Society Views Care Aides	7.3.1 The Perceived Bleak Future of Care Aides			

Table 7.1. Main themes presented and discussed in this chapter. The themes relate to the perceptions of power care aides experience during their role in long-term residential care.

Part IV will include a review of immerging issues central to the overarching theme of power in LTRC and how these issues affect how care aides viewed themselves as well as how they are viewed by society. Part IV begins with a review of the relationships care aides have with positions of perceived higher authority to them and how these relationships affect the care they are able to deliver to residents. The chapter will then review care aides' experiences in attempting to report as well as their perceptions surrounding the reporting process. Following this will be a presentation of how care aides believe they are perceived within the greater society. The chapter closes with a discussion of care aide perceptions of their future in LTRC, which does not appear to be positive, and, if this negative perception continues in its current state, how it will affect care aides' morale and sense of powerlessness.

7.1. Perceptions of the Higher Powers

It was a common viewpoint reported by participants that they felt they were the *"lowest person on the totem pole"* in comparison to everyone else in LTRC. The following section will review the participants' discussions pertaining to those who were perceived to have more power in LTRC than the care aides—their fellow co-workers, the RNs and LPNs, the management, and finally the care aide union.

7.1.1. Care Aide Union

The experiences of the care aide in LTRC is shrouded with notions of power and powerlessness, especially in relation to the other individuals and governing bodies in the LTRC setting. One of the common topics that was brought up in over half the interviews (n = 16) was the care aides' union. Interestingly, almost everyone (n = 12) who brought up the union believed that it assisted in perpetuating a mentality of *"unaccountability"* among the care aides because it *"protects bad care aides from being fired."* There were two participants who openly said that they do not follow the union or understand its rules: *"I don't follow it. I don't understand the union very well. I've never—yes. I don't know, I've never really followed the union. I don't know what the rules and stuff are."* Three participants were adamant that the union was their protector, but out of those, one also stated that the union helps keep bad care aides unaccountable.

There were significant incongruities reported in the relationship between the union and care aides. The care aide union is an organized association of workers formed to protect and further their rights and interests, or a labor union.

> We have nothing but our union. We have 50'000 strong supporting us from behind. But they're so many steps of things before we can ask for the union to commit and represent us that we have to do it on our own. **(Shelley)**

As in seen from this excerpt from Shelley, when participants were asked who they believe is there to support them, a common answer was *"the union."* The interesting point about Shelley's comment is that she states, *"we have nothing but our union."* This implies that beyond the union's support, care aides do not feel that there are any other governing bodies to protect them. There was an alarming discrepancy between the participants regarding what the union was thought to do for them and if the union was causing more harm than good. The union was often described as being a *"protector"* to the care aides. When one participant was asked what support she felt she had in her role, her immediate response was *"Oh, the union . . . they are awesome. They wouldn't let us get bullied or pushed around too much. That's for sure."* This excerpt reveals that this care aide believes that without the union, perhaps she would be bullied or pushed around.

Another participant shared her experience of how she felt the union was there to support: *"When I first came in [to Green Lodge] I didn't have a [care aide] number because I didn't know that I was supposed to have one . . . because I'm from [another province]. Yes, and so the union stood up for me to get my number."* Still, another care aide with almost three decades of experience reported the relief she felt by having the union by her side when she was injured on the job and attempted to get paid time off:

> Because when you're injured, you're hurting, [and] not only do you try to heal yourself that way, now you're fighting a huge entity that you don't even know if you're going to win. You know? And I did. And I felt really validated when I did. And I have to say, thank God for the union, because they took over all the paperwork. And they represented me. And when I hear people complaining about union dues, I actually have to say, I get that, but, boy, if you need this, they're there for you. For that alone, it's worth it. You know? Because a lot of people won't go to that next step because it's so intimidating with the paperwork. **(Sandra)**

While it is apparent that many participants reported feeling protected, validated, and supported by the union, an equal number of individuals have remarkably different views regarding the union. For starters, often participants reported not knowing exactly what the union did for them. There was no consensus on exactly how the union works or what the union was able to do for the care aides in times of needIn the following excerpt, a participant discussed believing that the union was supposed to be on their (the care aides) side but not trusting that they had their best interests in mind:

Researcher: Do you feel like you're in control?

> **John**: Not really [laughs]. Yes, it's kind of like you're down. You're a vulnerable man on the totem pole, you know? You're down here. And the company is up here.
> **Researcher:** And where's the union?
>
> **John**: Well, [laughs] down here [laughs].
>
> **Researcher**: Is the union with you?
>
> **John:** Oh, they're supposed to be, you know? But sometimes, it feels like they're not. I mean, when we just run through this contract negotiation, it was a little bit weird. Like, they have been coming to us and saying, "Oh, nothing's going right. Nothing's going right. So, be ready. Within a week, we could be on strike." And then three days later, they came back and like, "Oh, we got this agreement. It's the best we're going to get. You guys need to vote on it." And we're like, "How do we know it's the best we're going to get?

It is apparent that John does not feel like he has power in his position within LTRC. It is also clear that he knows that the union is supposed to be there to support him, but he does not trust or believe that the union is doing all they can to protect and negotiate on behalf of the care aides. He also feels that communication between the union and care aides is poor and that the care aides are not treated equally or with respect. Further still, participants reported that sometimes the union is a barrier to building team cohesiveness among all levels within the healthcare hierarchy. As seen in a previous quote in this chapter, the union is also seen by some care aides to be a barrier to cohesiveness among the different levels of the healthcare team. The RN and LPN union are different from the care aides' union and, as such, they are not all covered collectively. They may resolve workplace issues, bargain, negotiate, and strike all at different times and for different reasons that sometimes conflict with one another.

The union is also seen by many as a source for protecting unaccountable care aides. As one participant reported, she feels the union allows for care aides to have too much job security: *"Everybody is—we're totally overprotected . . . And they'll just call in and they're all protected . . . when you're union, you can call in sick as many times as you have to."* Interestingly, there seems to be a sense of "not liking the union" for making sure the unaccountable care aides are overprotected, but also an appreciation of the union because it allows all care aides to miss as much work as needed because they are ill. Still, another participant described her frustration regarding the union interfering with what the management can and cannot do to support the care aides and the residents:

> I think the union fights against the admin. And then the actual ideas of why we're here gets lost by the wayside based on the fight that we have to have with each other. . . . Because there's times I want to go into my [director of care] and say, "You know, this, this, and this is just ridiculous." But it's a union thing, so I'm pretty sure I can't go in there and say that. So sometimes our hands are even tied. But then, if you want to ask me about the union, our representatives are one of the most bitter people here. **(Sharon)**

The frustration Sharon feels regarding the arguing between the two powers that be, the union and management, is evident. The focus of caring for residents, she feels, is lost due to two bodies of power not being able to find agreement. Another care aide does not seem to trust the union, as seen in this quote: *"Unions don't tend to look after the good ones. They tend to preserve the bads."* It is clear there was a huge discrepancy of opinions regarding care aides' relationship with the union and what the union meant to them—from protector and advocate to the mysterious overarching body that was a detriment to some.

> But I also think when people get into a union, there's a different mentality . . . Because my—this is my issue coming from where I was accountable for every hour I had to work, to coming here when you're union and you can call in sick as many times as you have to. There's no accountability. So, that's what starts the tower of teetering and falling over, is if the habitual person that calls in regularly never gets disciplinary action, then they're going to constantly continue to call in . . . That then shortens the team, which then draws stress to the team, which then filters down for care. That's where I see the hugest setback on a daily basis. The biggest day-to-day problem is being short-staffed. It's not necessarily the administration's fault for not staffing it. It's the accountability of the employee and the fact that there's no actual repercussions. **(Sharon)**

Again, the accountability of employees is a point of frustration that was brought up by several care aides. It appears that care aides are perceived to not be held accountable for their role in LTRC, and there are limited negative repercussions because of their decisions that negatively affect the system of order, namely the amount of care staff on shift. As a result, this negatively affects the experience of care aiding as well as the quality of care for the residents. As Donna shares, there is the perception that there is very little that can be done about this by the care aides:

> Oh, you can't really do anything about it, unless they do something terrible, you know, like abuse the resident or—you know, just do something bad. You can't just complain about them and be like, "They shouldn't be a care aide," and then get them fired, because it's just not going to happen. **(Donna)**

Donna’s final statement is indicative of the powerlessness that participants shared during interviews; even if they complain, the changes that the care aides request are *“just not going to happen.”* In this sense, the care aides express their own feelings of being powerless to make changes they see necessary to accomplishing the role they have been trained and hired to complete.

7.1.2. Management

The management team at Green Lodge includes the General Manager, Director of Care (DOC), Recreation Therapy Manager, and Business Manager. There were discrepancies between the perceptions of management among the care aides. Where some individuals believed that management was doing a good job, others believed management was a part of the problem in helping keep poor quality care aides employed at Green Lodge. Jennie, a 44-year-old Hispanic woman with 12 years of experience as a care aide in LTRC, shares her thoughts about the importance of hierarchy in LTRC:

> I’ve heard some girls say that they think they’re being bullied, but from what I hear, it sounds more like they’re being disciplined. And I agree with—sorry, I agree with management [laughs] . . . I’m glad that more new management has come in and they’re starting to discipline the staff more. Because I have seen lack of that in the first year and I was just like, “Really?” So it seems like these guys are more aware and they’re doing more stuff, and I think that’s great, because I think in this job, you need to be accountable for what you say and do and act. . . .
>
> I hear from a lot of RCAs that they feel like they’re not appreciated, they’re not cared—they don’t care about them and they say that they feel like they’re on the bottom of the totem pole. I’m not saying that’s how I feel, but that’s what I hear a lot. . . . But I think you need—you got to understand hierarchy too. Like, you can’t all be leaders and you can’t all be at the top. Someone’s got to lead, you know? Doesn’t mean you should be treated like garbage. **(Jennie)**

There was a consensus among participants that there needed to be discipline in care aiding. One participant called it the *“wild west”* out there with all the *“no fail”* schools *“pushing people out.”* It appeared that care aides need some stronger structure in their role to help them do the best they can. They count on the management to protect them from working alongside care aides who are a liability to themselves as well as to their residents and fellow staff members. Apparently, management and union are not working symbiotically with one another, and this tension is causing the care aides to mistrust both the management and the union.

However, although some participants had incredibly negative views of management, some reported that they perceived management as doing their best to show appreciation within the limited budget and time constraints present. As one participant reported, *“Administration does try hard to let us know we are appreciated based on the budget they’re given.”* Care aides appeared to understand that management is also a character in LTRC that does not wield unlimited power, money, or prestige and, as such, is only able to work with the allocated recourses that are at hand. One participant who had left Green Lodge to work for many years in the community and then returned stated that she felt incredibly supported by management: *“[Management] always tell me, “We’re so happy you’re back, we’re so happy to have you.”* This verbal appreciation was something that participants would occasionally report. The comparison of management styles and policies among the care aides was routinely discussed. The current management at Green Lodge in relation to the management employed at previous LTRC facilities, or even management that was previously employed at Green Lodge, was a point of discussion for participants. When one participant was asked what management did at Green Lodge that she apparently appreciated so much, she responded:

> [In the previous facility], there was no respect . . . There was a lot of harassment from the management. They kind of looked down their nose at us as, like, below them or something. It was horrible. It was a very bad experience. [At this facility] they kind of stay out of our way . . . , I don’t feel they’re looking at us. I don’t feel that at all. Like, the place I came from [the other LTRC facility], they’re always walking down the hallway and checking up on us. Oh, it’s brutal . . . It was horrible . . . You’re always on guard, where this place is—I never feel guarded. And I always hear from management, “Thanks for coming in. Nice to see you.” And it’s so nice to hear that. I love that. . . . [At the other facility] I just felt, like, unappreciated and just always kind of, like, “Let’s catch her doing something wrong,” kind of thing, constantly . . . it’s intimidating. **(Stephanie)**

From the perceptive of the participants with experience working as a care aide in other LTRC facilities, it seems that there are huge differences between the management styles and leadership abilities held by management. Even though in the previous quote from Stephanie she lamented about the LPNs, it appears she does not relate the fact that management hires the LPNs to it being management’s fault that, as she perceives, the

LPNs are poor quality. From Stephanie's experience, it is apparent that she went from one situation in which she felt untrusted, monitored, bullied, and harassed to her current situation at Green Lodge where she feels she is appreciated and relied upon to deliver good care to her residents. One participant reflected on the high quality of the management team at Green Lodge: *"I came from a place, I thought it was—the care was okay there. I thought it was pretty good. I came here—this is an unbelievable facility."* Another participant explained*,*

> Like, look at the places that are working really well that maybe need a little bit of tweaking now and then. Like, this place is really well managed. And the residents are happy. If the residents are happy—I even go around and talk to the residents. "Are you happy? Do you like it here?" . . . We can just tell by looking at people's faces too. **(Heather)**

Although participants would share when management would give them verbal appreciation and some felt the happiness seen in residents was reflective of good management, not all participants appreciated the management team. An excerpt from field notes describes how one care aide reported being discouraged and annoyed because she felt that neither the care aide educational system nor the management within LTRC understand the current state of LTRC and the role of care aides: *"[A participant] told me it was frustrating going from school and management, where she feels they are both out of touch and do not understand the reality of caring in LTRC."* It is apparent that the participant that this note was written about was frustrated to see two groups of people who have a significant impact on both the care aides and the residents' lives, as well as on the potential to make positive differences in these populations, not be fully aware of the realities inside LTRC.

> But that's the thing with the care industry, it's a two-way street. If you do a good job, you're appreciated. By the residents and by management. . . . They're fantastic here, I've got to tell you, absolutely wonderful. **(Jim)**

Some care aides openly mistrust authority and, hence, do not trust the management, as one participant reported: *"I never did [trust management] [laughs] . . . I don't trust anybody. I take care of myself."* Some participants reported feeling excluded from team communication and decision making by management based on favoritism:

> Sometimes . . . there would be employees that would talk to the management. And the management would listen to, like, specific cliques of employees. And then the other ones that doesn't belong to that clique, even though they talk to them, their voices wouldn't be heard or wouldn't be considered. **(Cynthia)**

Generally, the level of appreciation and trust held by care aides toward the management at Green Lodge was relatively stable; however, it was brought up by participants that management was in charge of hiring the care aides and, as such, they could be more proactive in removing unsupportive care aides:

> They could [get rid of bad care aides], if management did their job. If management did their job properly, yes, and started observing, listening to other people, listening to the nurses, writing a warning, [and] if that didn't change, write a letter. You get three of those on your file, [and] those [are] grounds for dismissal. **(Sandra)**

It is interesting that in some interviews participants directly related the fact that they work with several less-than-suitable care aides. In fact, the question, *"how many care aides do you believe are currently employed, or that you graduated with (not necessarily working at Green Lodge), that you believe should not be care aides?*" quickly became a question that was asked during interviews whenever enough rapport was built and it could naturally be asked in a conversational manner. Out of the 16 participants who were asked this question, the average response was 24%, and responses ranged from 5% to 55% of those they believe should not be care aides. Elaborating on this, Patricia shared:

> I'd say about 20%. . . . I've seen some really good ones, and then I've seen some pretty [shitty] ones. I'm not doing it just here. I'm doing it as an all around . . . If I'm doing it just here [at Green Lodge], I'd probably say about 5%. There's not too many people upstairs [on the complex care floor] that I would—There's only a couple that I say, like, "What the hell are you're doing here?," like, no compassion, no nothing. **(Patricia)**

When Patricia states *"all around,"* she is comparing Green Lodge to the other two LTRC facilities where she had been employed regarding those who she believes should not be care aides.

This section reviewed the perceptions that care aides shared regarding management. The next section will review the relationships care aides shared pertaining to the nursing staff.

7.1.3. Nurses

Perhaps the relationship where the most friction existed was in relation to the professional nursing staff. In LTRC, both Licensed Practical Nurses and Registered Nurses (LPNs and RNs) oversee the work of the care aides. There were obvious differences when participants would speak about RNs compared to LPNs, and they reported great variations regarding their relationships with these two groups in LTRC. The nurses viewed RNs as *"pill pushers."* And because on shift care aides mostly interact with LPNs (the ratio for LPNs to RNs is larger), the participants had more to say about the LPNs.

There were discrepancies reported between the apparent respect held by participants toward nurses as well as the reported respect that participants perceived the nurses felt for care aides. Participants would sometimes belittle the role of nurses and call them *"pill-pushers,"* since one of their tasks is to give medication and often in the form of pills. As discussed in Chapter 2, although LTRC facilities often espouse a person-centred care environment, most of these settings act within a biomedical-driven model. Since the nurses have the authority to administer pills, they are seen to have more power in LTRC. On the other hand, because care aides do not have the authority to administer pills and must ask a nurse every time medication is needed, care aides are perceived to have less power and must negotiate with the nurses for the power of administering medication to residents.

> We are not heard at all. And we're not supported. We're not heard. <u>Our LPNs are a joke</u>. I'm sorry. I'm just going to say it openly. Half of them got grandfathered and they've never even taken the RCA course . . . Yes, that are grandfathered in, that have never taken the RCA course. All they do is supposed to pop, pop, do the computerized thing and crush meds, and disperse them. That's all they do . . . They don't know what lift to use. They don't know what sling to put on the residents. They don't know how to properly do it.
>
> And the leadership is just—they're dauntless. There's no leadership skills. They think that they're in such a big class above us. . . . Like, most of them are stupid little peons. Yet, we don't tell them. **(Shelley)**

It is apparent that Shelley does not think highly of the LPNs that she works with and does not see value in their role or capabilities. Shelley also highlights that she feels

LPNs *“think they are in such a big class above us,”* which recognizes that LPNs hold more power in LTRC than the care aides and that she does not approve of this. In comparison to Shelley’s perspective, Jenny believes that communication between care aides and LPNs has gotten better:

> That’s one thing I do notice here over the last two years is this. In the last year, I noticed that there’s more communication between the LPNs and RCAs, and it seems to be more respectable now . . . And some of them were friends with some of them. So, it’s—that’s going here and I love that. . . . And the RNs, like, I go out with some of the RNs or one of the RNs—and we’re friends and it’s so good. It’s our job, we don’t look at it like, “Oh you’re an RCA, oh.” **(Jennie)**

Other participants reported a strong collaboration and respect among care aides and nurses regarding their respective work roles. For example, a participant reported that he felt the nurses are always welcoming and happy when he is on shift because *“they know I’m going to do the work. I’m not going to leave a mess for the rest of the staff to have to clean up*.” The care aide appears to be boasting about his ability to do a good job, but he is also sharing that the nurses, and he himself, perceive fellow care aides as creating more work in the form of a *“mess”* for the nurses to *“clean up.”* This is not a collaborative attitude that is aligned with the care aides’ role, but instead with the nurses’ role. As such, it appears this care aide is identifying himself as someone more valuable to the nurses than just a care aide—he is a care aide who helps the nurses perform their role. As such, this quote could also be interpreted as a power statement in that this care aide perceives he holds more power than the other care aides because he perceives he is more valued than those who *“leave a mess.”*

The notion of *“better than”* was often reported to be felt by participants from nurses, especially LPNs, implying that LPNs hold more value and thus power in the LTRC setting in comparison to care aides. Participants discussed feeling *“looked down on”* because they were *“just care aides”* and not nurses. This feeling was especially salient when participants discussed working with LPNs who had once been care aides but who went back to school to get further education to become an LPN. This resentment toward LPNs is apparent in the following response from a participant who was asked if she felt that the nurses understood the role of care aides: *“No. . . . Some of them do because some of them have been care aides. . . But a lot of them think that—oh, no, now that they’re LPNs,* *they're superior, you know?"* The impact of this notion that nurses were "superior" to care aides was reported by participants to apply itself negatively to working practices and relationships, including inhibiting the communication between care aides and nurses. It was understood among participants that the line of communication between the two vocations was often unclear for a variety of reasons. As one participant reported: *"I just mean sometimes us, as the care aides, don't always communicate good with the LPNs and the LPNs—you know that—so there's kind of the lack of chain, like, conversation between them . . . And it's because of policy. It's because of union. It's because of peer pressures."* This quote highlights participants' perceived reasons as to why there are such barriers between the different characters in the healthcare team. She does not point her finger at individuals, but instead calls out the lack of communication between nurses and care aides as a fault held by competing interests outlined in the policies. The various unions that oversee the work of each profession are further seen as fracturing communications. More important, however, is that she highlights an influence in the form of *"peer pressure"* within these two groups to act and behave in such a predetermined way toward one another. The power differentials between care aides and nurses could play out in explicit ways and could result in care aides feeling pressured and bullied by nurses. As Mellissa, a 32-year-old Caucasian care aide with 2 years of experience, shared:

> [If] you try to tell your in-charge nurses on your wing [something about the residents' care], they're the boss, right? They like to—Well, some like to bully and push you around . . . It sometimes will stress people out and ruin their day and [they will] snap back. But at the end of the day, it's not the residents' fault, but it could stress them out. **(Mellissa)**

This participant speaks to care aides reporting feeling intimidated by nurses by directing the care orders in a way that they have deemed correct. This participant draws light to the fact that this negative interaction may then affect the care aides' attitudes, which may then impact the care they deliver to residents.

While the most direct and obvious power differential was between the care aides and the LPNs, power issues were also expressed as pertaining to other components of their role as a care aide. The next section of this chapter will review the care aides' perceptions regarding the environment in which they work in LTRC.

7.1.4. Perceptions of Long-Term Residential Care

It was common for care aides to discuss LTRC as an *"industry."* The dominant feeling of frustration and hopelessness at the current state of LTRC was evident. In every interview in which the state of LTRC was brought up, care aides shared their negative perceptions, or as one participant shared, *"It's a frustrating industry."* Participants believe in the capacity for LTRC to do a better job in supporting both the staff and residents better, yet they also see the barriers preventing these good care practices from occurring. The following section discusses the participants' perceptions of LTRC, as well as how they view their role within this setting and, finally, how they believe society perceives their work.

Participants often reported discouragement in relation to *"having their hands tied"* in delivering the quantity and quality of care to their residents in such a task-based environment. They reported being *"under such a time limit—getting people up, getting their meals. . . . we just really can't change anything."* This participant continued by saying that she *"thinks [LTRC] is functioning the way it is, but it's kind of . . . It is what it is."* This feeling of acceptance is an overarching theme throughout many of the interviews. Another often-reported realization by the participants once within the LTRC system was that the residents, whom they care deeply for are being "warehoused," which is not an ideal option for the residents. They also discussed how they see this form of housing as a profit-making model where the focus is on the *"bottom line"* and not on caring for the needs of the residents housed within. The following quote highlights this perspective:

> I'm not a real big fan of warehousing [residents]. Well, I call it "warehousing"—95 residents on the floor. And they're all complex care, all different types of dementia, all different psychosis. And I don't think it's a good thing. . . . Warehoused. I mean, it's the more you have, then the more profit to it. **(Betty)**

An interesting component to this excerpt from Betty, who has over 30 years of experience working as a care aide in LTRC, is that she openly describes that she believes residents are being warehoused inside a profit-making model that is detrimental to the residents' health. Yet, her role in this setting is to deliver good care. Therefore, Betty is put in a position where she is destined to fail at what she is supposed to do, not for any fault of her own or lack of capacity on her part, but because, as she states, LTRC is a warehouse environment and not a caring environment. As shared in Chapter 6, sometimes care aides would leave their shift feeling disappointed and frustrated because they *"were not able to do their best job."* It can be understood that working in a situation in which you are continually destined to do a job that you know is not your best is a very disempowering situation.

More important, even though participants openly recognized that there were flaws in the system, they were able to rationalize an unchanging situation. After all, there are flaws in every system, so LTRC is what it is. As one care aide shared, *"that's just the reality of any job. You're going to have lazy ass workers that make the same money as you that don't do the work."* There appeared to be a sense of acceptance in this sense: it's not the best environment to deliver care to residents, but it is also not the worst. It was apparent in some interviews that participants had initially entered this occupation with the vision of having the opportunity to give exceptional care in supportive, fully resourced, and welcoming environments. Still, other participants made it clear that they were aware of the state of LTRC, but they believed that, somehow, they would have the capacity to make it better, as in the case of Ryan, a 55-year-old Caucasian care aide with 13 years of experience:

> I try to garner some support from the other good care aides who have been doing it 15, 20 years, and they go, "Yes, Doug, yes." But they're tired. They're tired of the job. They've been through so many care aides, worked with hundreds of people. I've only been here just two years and two months, and there's 36 people below me on the [care aide staff list]. **(Doug)**

Regardless of the disinterest of others, care aides consistently reported their own innovative ideas of how to change the current state of LTRC. They often discussed something that has been labelled in this study as the "Scandinavian fantasy." These care aides have heard or read about some amazing LTRC facilities in The Netherlands, Denmark, Sweden, and Finland and believe that if only Green Lodge could be modeled after those facilities, there would be no issues or barriers to good care practices and it would be a nursing home utopia. In this type of setting, both the quality of care and support afforded to the resident, as well as the support given to the staff, would be exceptional. Some care aides would make comments like the following from a participant with a dozen years of experience: *"I honestly believe they need to take the profit out of . . . I mean what does Switzerland do? Like some of these countries.*" This quote speaks to the sheer frustration of care aides delivering care in a situation that is led by the accumulation of money and not the capacity to deliver good care to humans. The Scandinavian fantasy was evident early in the study:

> Care aides have often mentioned this "Scandinavian nursing home utopia." They talk about how they do things in Sweden, Norway, The Netherlands—often different places, but all talking about how those countries do "resident care better" . . . The majority of [participants] want to be able to give better care and believe they could if they were not in this situation. **(Field Notes 09.08.16)**

Sometimes the Scandinavian fantasy transcended geographic borders and applied to the treatment and preparation of care aides themselves and not necessarily to the residents. For example, one care aide with 7 years of experience discussed how *"in other countries . . . [their care aides] have to do exercises and stuff before they go to work, and [they all do group] stretching [before a shift]."* This quote sheds light on the fact that care aides, alongside their residents, do not feel well taken care of and appreciated. In a sense, care aides may also feel warehoused alongside their residents, which will be discussed in greater depth in the following chapter.

Another perspective that some care aides had who had not grown up with exposure to LTRC environments was that LTRC was a foreign and unattractive concept to caring for older adults. One First Nation participant elaborated on this notion by describing how it was difficult to come from a cultural background in which older adults are held in the highest and most respected esteem to one in which older adults are seen as shut out from the rest of society and without their own autonomy. He described how it was challenging to follow through on his care tasks instead of letting the residents do as they wished:

> It was tough coming from a First Nation's background to a facility . . . Yes. Because our elders, when they spoke, we stop and listen. What they said was pretty much like law. So it was hard for me to adjust to a facility. Somebody told me that they just want to stay in bed, and they refused care. And I said, "Okay." I walked away I got told "come back here and get that person up!" Yes, because I don't run into too many dementias or any kind of Alzheimer's on First Nation land. **(Brad)**

It is clear from these interviews that care aides want to deliver good care to their residents. They want LTRC settings to help them facilitate their delivery of care, and yet they are overwhelmed by the barriers that stand in the way of this happening. Care aides come to the employment setting for a variety of different reasons, but regardless of how they got there, they are not satisfied with the current state of how LTRC works. The next section will discuss how care aides view their own role within the LTRC setting.

7.2. Care Aide Perceptions of Their Role in Long-Term Residential Care

There was a consensus among care aides in this study that they believe the following: care aides have an important job and they are uniquely suited to do this job successfully. As is highlighted by a care aide with 10 years of LTRC experience, their role is different than that of other health professionals, such as nurses, but it is still vital and in need of acknowledgment: *“We may not be a nurse or anything like that, but I think it’s caring and compassion and . . . would—if residents don’t get the quality of care that they get, to be perfectly honest, I mean, the care aides are the ones that are keeping them alive.”* Still, another care aide outlines what she sees as some of the noteworthy differences between the roles of nurse and care aide:

> I mean, the ladies who taught me when I was in school were nurses, which is like, okay, the nurses know a lot of stuff. However, the nurses do not do a care aide’s job. Nurses do wounds and medication and stuff. [But] they don’t do the getting [the residents] up in the morning and taking care of them and dealing with the panic attacks and dealing with the freak-outs, like, they don’t do that. **(Jane)**

There was a consensus among participants that not everyone has the capacity needed to be a care aide in LTRC—patience, empathy, and the ability to multi-task. As one care aide shared, *“The new people that are good, that have a positive attitude, they go, ‘Yes,’ and they have empathy. You can see it.”* Participants took pride in the fact that they made *“the cut.”* The ability to be a good care aide in LTRC is described as one that is innate and not necessarily something that can be learned. As one participant reported, to be a good care aide *“75% should be in you already, and 25% you learn in school.”* She continued by saying *“they can’t teach you patience. They can’t teach you [empathy].*” This quote emphasizes the importance of two traits that were repeatedly highlighted by participants as embodying a good care aide: *empathy*, or the ability to understand and share the feelings of another, and *patience*, or the capacity to accept or tolerate trouble or suffering without getting angry or upset. During interviews, participants shared a sense of pride in believing they had both traits and thus they embodied the key elements of being good at their role.

Along the same lines of being uniquely suited, care aides understood that their role in LTRC is difficult and not everyone is cut out for this type of work. They reported that the type of knowledge they have may not be, in the words of one participant, *"book smart,"* but that it is a form of understanding that is necessary to be successful in their role in LTRC: *"[Not everyone is supposed to be a care aide] . . . Some people are book smart, but hands-on smart? Not so much."* Care aides would also make comments regarding the often graphic and distressful nature of what they are witness to. As one participant with 5 years of experience explained:

> I mean, it is a tough job . . . I don't know. I'm thick skinned, I guess [laughs]. . . . It's not easy to see some of the stuff you have to see in this job. **(Jane)**

Jane's quip about having *"thick skin"* makes apparent the fact that she bares witness to circumstances and situations that she finds difficult to process, but she does so simply because of who she is. In the face of difficulties, she can continue with her work and doesn't let these events distract her from her role of care aiding. She values her *"thick skin."*

Coming back to the perceived pit-falls of care aide education, participants would remark on how obvious it is that there are courses that have *"no-fail"* policies for care aide education. They reported that it was clear to the experienced care aides when they are working with a new care aide who should not have have been allowed to graduate. The following quote from a participant with 16 years of experience in LTRC highlights the frustration felt by seasoned care aides who feel they must use their time to educate and train other care aides who should never have been allowed to graduate, because their skill sets for delivering care are so abysmal and they are clearly unprepared for the realities of the role:

> I would probably say, well, a quarter of them [should not have graduated to become a care aide]. That's just my guess, right? That's a rough estimate. Let's say 30 in the class, I'd say. Yes, probably five or six of them . . . You can tell the ones that

> should [not have graduated]. They can’t even make a bed. They can’t make the bed with [a resident] in it! **(Gwen)**

Care aides are often thought of as the *“eyes and ears”* in LTRC, and yet when it comes to their actual power within LTRC, their ability to express and record what they see and hear is almost non-existent. Although they are the eyes and ears of LTRC, they have no, or a very limited, ability to voice their concerns. The following section will review participants’ accounts of how reporting occurs in LTRC, their coping mechanisms for dealing with the stress of their role, and the perceived bleak future they believe is inevitable for the role of care aides in LTRC.

7.2.1. Reporting: Screaming into the Void

In these incidences, participants shared that they felt nothing happens when they report abuse. Participants discussed how they perceive it to be risky behavior for care aides to report abuse when often the outcome is only a large amount of mundane paperwork (that the care aide is already intimidated by or does not have time to do). Often, nothing is done after the reports have been completed or in many cases the reports are never even completed. One participant stated, *“I have been struck . . . and other care aides [have as well] by a very violent resident in front of a nurse and nothing has been done about it.”* Participants discussed how they are not being allowed to do their own written reports: *“We do not have the authority to fill out an incident report. It is the charge nurse that does it. And it’s her that decides whether or not she will write it out.”* Care aides who verbally report to their head nurse discussed being concerned that the higher levels of healthcare were upset with them for speaking out: *“I’ve been known to go to the office. And the nurses probably are frustrated with me because I will say things . . . Yes, I don’t keep it in.”* In this quote, it is interesting how this participant states that although she knows that one group may be upset with her, she will not keep silent regarding situations that she feels need to be reported. She believes she has a *“duty to report.”* In other cases, this duty to report is present, but participants express feeling that it is a futile task.

> It feels a lot like you’re screaming into the void a lot of the time. Something’s going on. You know something is going on. You say something about it. And you just don’t get an answer, or you’ll kind of get this non-committer, like, “Oh, yes, we’ll look into it.” **(Jane)**

Participants regularly reported on their frustration that if a resident assaults them on the job, other than a verbal report to their head nurse they have no capacity to record and document the occurrence. As Helen describes:

> If a resident slaps me during care, all I can do is go to a charge nurse and say, “While I was giving care, this resident slapped me in the face.” . . . That’s all I can do. And, like I said, if it’s not documented, it didn’t happen. I have been struck myself and other care aides [as well] by a very violent resident in front of a nurse, and nothing has been done about it . . . There’s nowhere I can—they’ve taken all that away, where I can physically write or chart myself “violence,” that kind of thing . . . and that would also alert the other care aides coming on shift . . . And also if it was documented, it would also maybe help to prove in certain situations that that resident is not appropriate for this facility. **(Helen)**

Helen expresses concern for her own safety as well as the safety of other care aides who in the future will be delivering care to a resident with possibly violent tendencies. A comment that was repeated by care aides was, *“if it isn’t documented, it didn’t happen.”* Helen also highlights how even when care aides do report to their head nurse, it is up to that nurse to decide if it will be documented or not. Sometimes participants would recount stories of when they feared getting reprimanded because of their request to report maltreatment, as one care aide described:

> I can verbally report . . . I remember, like, one time I walked into a room and I found this person, like, all mangled on their beds, so I phoned my nurse to show them and the nurse got mad at me for having my residents position them. Like, “I just got here, I just walked in. I just phoned you to tell you what was going on and to report this incident and to help me move this person.” Because I can’t move this person on my own without injuring me or the person. And what if that person’s injured? [Laughs] . . . I didn’t get in trouble but, yes, I just was like, “I just called for help, just be calm.” **(Linda)**

Linda expresses her frustration that her account of the situation was not fully heard by the nurse involved and that she was originally blamed for a situation she was not to blame for and was instead attempting to remedy. Despite not knowing whether their report would be deemed worthy of being recorded or not, participants discussed a number of other reasons why they would choose not to report, including not wanting to report to their head nurse for fear of being a whistle-blower, or a complainer. The politics of LTRC seem to allow for the bullying, gossiping, and social shaming of someone who has *“ratted”* or *“tattled”* on a fellow employee, as one participant reports: *“If you pay attention to everyone* *else, the actual care aides, there's a lot of back stabbing, like people saying stuff behind other people's backs . . . or running to their nurse and tattling . . . complaining to their nurse about [something]."* Sometimes participants discussed how if they reported on a care aide they perceived to be delivering poor care or acting in an abusive manner toward residents, they would then become the target of bullying themselves. For example, Cynthia shared a story about the bullying she experienced in a previous facility where she worked before coming to Green Lodge:

> I reported to the nurse . . . how this person did not do care on this specific resident. And since this employee is a friend of the nurse, nothing got done. They just talked about it and . . . started bullying me at work and everything. I reported and then she messaged me on my Facebook. . . . [then] she messaged me on my phone number because all our phone numbers are on the staff room posted. So I have to pull it out. I had to text the management. I said, "You . . . have to pull out my number from that wall because I've been receiving private message. And if this happens . . . " So I reported to the management consecutive instances of that. And they did nothing. . . . I just went home crying because I can't provide proper care, right? . . . [If] you have anxiety like that, you can't be providing care. But still, she's still there. And they are holding onto her for the longest time. It's so not nice. . . . That's why I quit there because I don't like stress in my life. It's not nice. **(Cynthia)**

Cynthia recounts how reporting poor care delivered by another care aide caused her to then be the target of bullying and how the bullying became so severe it affected her home and private life. Cynthia reports that when one is bullied, the person is either left in such an emotionally distraught state that he or she does not have the capacity to deliver good care to residents or must accept that he or she is powerless to stop poor care delivery.

There appeared to be an accepted culture of silence among some participants regarding reporting incidences of bad care. For incidence, care aides often feel that they do not have the power or the time to report abuse they see toward residents because they do not want to stir up further confrontation. As one participant reported, *"I've never really dealt [with bullying]—I don't really deal [with bullying]—I'm not very confrontational."* Unfortunately, it is this viewpoint of disliking confrontation that seems to be a barrier to reporting accounts of abuse, neglect, and bullying. As one participant described:

> **Researcher:** Have you ever seen staff-to-resident bullying?
> **Linda**: Yes. . . . It was just like pressuring them into, like, I don't know, like, it's their own home. Like, they getting them up in the morning, like,

> I know that like we need to, like, give them their care and stuff, but like some of them, like, they refuse and refuse and be violent. I don't know.
>
> **Researcher:** And then what do you do?
>
> **Linda:** It's so hard. Like you just need to bring in another person, like—Oh, there's one incident. I remember it was one care aide who wasn't listening to a resident and . . . swore at them and . . . slammed the door in their face.
>
> **Researcher**: Swore at the resident?
>
> **Linda:** Yes.
>
> **Researcher:** How do you respond [when you see abuse]? What do you do?
>
> **Linda:** I don't know . . . I hate confrontation.

This notion of hating confrontation may stem from the fact that care aides feel powerless to change anything in LTRC, so why put their own safety and well-being at risk. It is not just care aides who are believed to be without a voice in the LTRC environment. In one case, a participant recounted a story where a housekeeper witnessed abuse and decided against writing it up.

> I think I'd been here six or eight months and said, "The housekeepers brought to my attention this resident was abused today by this person." The housekeeper at first said, "Oh, yes. I'll write a note." . . . Well, she got home and her husband that sits on the board of the union says, "Oh, no. If you make a statement like that, this person's going to get to know who their accuser was and defend himself." And she didn't want to be blacklisted, so she decided not to write a note. And nothing was ever done about it. This person is still working here to this day. And that is frustrating because this person, you know, I've questioned a lot. **(Judith)**

This notion of being *"blacklisted"* for reporting alleged abuse seems to be a timeless occurrence; yet, considering that these situations are prevalent in LTRC with arguably the most vulnerable populations is abhorrent. Judith makes the point that because this person did not write a note, nothing was ever done, and this person is still working at Green Lodge. This begs the question, why hasn't Judith written a note? It appears that, akin to the housekeeper, Judith is also in a powerless position and will risk being blacklisted if she reports. The situation appears to have many layers and, understandably, they are only compounded when cultural differences are added to the equation. As in the case of an interview with a Filipino participant who replied *"yes"* when asked if it was because she was in Canada that she did not report the bad care and bullying that she saw. When she was further asked if she would feel more confident to report what she saw if she was in the Philippines, she also replied *"yes."* It is apparent that measures must be put in place to support care aides' ability to report abuse and bullying to ensure that the *"eyes and ears of LTRC"* are able to have a voice and be empowered to prevent further abuse as well as initiate positive changes toward their work and the delivery of care to residents.

> One of my residents the other day, I noticed there was something different about her when I was helping her to get dressed. And then I got her into the bathroom and she was sitting on the toilet and it just—I knew there was something wrong because her right side—the—her motor skills were going all wacky. Her arm was going like this. And her leg was doing this. And I'm just—I just was—So, I called him to come and assess her right away because. Yes. And he just said, "Oh, yes, that's just her dementia." And I'm just like, "Yes, but she's never done that before, ever." "Oh, no, it's just part of the—you know." And I'm just like, "Okay." But, like, to me, I just would have wanted something more out of him. I know he's just an LPN, but I would have—I don't know. I just—I even said—in the next shift, I said, "Just watch her . . . " I don't know. **(Karen)**

Interesting how Karen states *"he is just an LPN."* Karen also recognizes that the LPNs do not hold as much power as nurses, but they still have more "say" over care plans than care aides do. It is apparent that care aides feel they do not have autonomy over caring for their residents, they do not have their own staff meetings as the nurses do, they do not feel appreciated by management, and they do not feel confident that what they report will be documented. They feel powerless inside a system they know is not working as smoothly as it could. Care aides are the *voiceless majority* in the LTRC setting, alongside their residents—they see issues but do not have the authority to implement transformations.

> We used to have our charting where I would write down, "Blah-blah-blah has skin integrity issues." Nurse Christina, where? And then, I'd sign my initials because it's a legal document. Well, they took that part of our charting away. Now we just verbally tell them and hope that somebody does something. But I know my job is done because that's what I'm supposed to do.
>
> I don't follow up with the LPN to see what they did about blah-blah-blah until I'm like, "This person now needs a dressing," because I'm not the only person that cleans this person's ass. There are people in between. There are casuals. There are people that are on my days off. We're not working together here because they're not being told in a report . . . They're like, "What? That's not written anywhere." I'm like, "Not my job. I'm not a nurse." . . . We get held accountable for everything. **(Shelley)**

Apparently Shelly thinks care aides are held responsible for more than what they actually have power over. In this instance, Shelley notes she notes that *“I’m not the only person that cleans this person’s ass.”* She wants to report that the resident needs a dressing so that the other people who clean the resident are aware. Yet she is not responsible for writing, reporting, and charting anymore—that is the nurse’s job. She is frustrated that the residents’ care may not be consistent and they may decline due to her inability to record her residents’ needs and share with the wider care team.

7.2.2. Accountability Needed

This notion of accountability was brought up several times during interviews. While some care aides believe they are held accountable for everything (as in the case with Shelley), others wished care aides had more accountability. In one interview, a participant described how she does not view care aiding as a profession because there is no accountability or governing body overseeing it, which were viewed as helping both the residents and the care aides. As Sandra, a 55-year-old Caucasian care aide with 27 years of experience, explained when asked, *“Do you identify as a healthcare professional”?:*

> You know what, I don’t. Because—and I don’t know if that’s from working here in this—over the long-term being beat down. But because there’s no license, it’s a certificate. There’s now a registry because of the private schools that are just cranking out people, there’s almost no accountability . . . I feel like I’m just a care aide. I’m just somebody who—and I’ve heard this before, “wipes butts,” yes . . . I mean, I would love to see a licensing thing come in. And I know it’s going to mean money, but it’s also accountability, like they do for LPNs. . . . Yes, because we actually do a lot of the work the LPNs used to do. They’re doing a lot of the work the RNs used to do now. So, everything has changed. And at least, in that respect, there’s some accountability to whoever, a board, whatever. But you’re paying for a license. There’s some respect there. We’re then considered part—a valuable part of a team. Because here, our voice is not heard. And I’m sure in other facilities, it is heard, you know? But here, particularly, it’s not. You know?
>
> And I’d like to see the scope changed, more responsibility. I mean, the one I worked at before, we did medications . . . There’s nothing to do in medications. We’re on a blister pack . . . In fact, we could probably do it a little safer that’s not taking away for some of them [nurses]. But some of the nurses I see popping out and leave and walk away. And we’re going back saying, “Some of these [were] left. Nobody took it.” Anybody could take it or put it in fluids and leaving it with the table with four people where one of them is known to reach and drink her—not her

> own stuff. . . . And I know time, sometimes, changes things. And you do cut corners, right? But it’s not rocket science, because it’s all blister pack, right?
>
> And then the communication about—like, if there is a med change, at least we’d be more aware . . . With the other place I worked at, because we did the medications, I myself took it upon myself to research the medications because I’m handing it out. I want to know what it does. I want to decide if that’s . . . I think everyone should be educated on that if they’re doing it, right? But then, I could be more aware of what was happening with that resident. If something turned a different way, I could think, “Okay. Well maybe it’s the side effect of this medication.” We’re not given that. That sometimes, in the report, they’ll read something that was charted from a nurse. And then, “Oh, you, guys, don’t need to know that.” . . . So that just kind of tells me that my observation isn’t important then. You’re telling me that I’ve got no skill. And what I’m observing isn’t important to you. **(Sandra)**

The frustration that this participant shares is evident regarding her limited scope of practice. The one example she draws on is how she was allowed to do medications at one facility where she had previously worked, but at this facility they are not allowed to do medications, and she says that not only could the care aides do it and possibly do it better than the nurses, but also that it would free up the nurses’ time to do other tasks. It is interesting how this care aide wants more accountability and wants more scope of practice. She openly states that she is aware of how others in society see her and that she does not feel as though she is a healthcare professional in this setting. But she also has ideas for how to help care aides become healthcare professionals as well as valued members of the healthcare team.

7.2.3. Unsupported in Their Role

Unfortunately, care aides shared that they are not able to deliver the type of care they would like for their residents because of the barriers that stand in their way, including being understaffed, under resourced, and over populated with residents with complex care needs. Care aides stated that not having access to equipment was also a barrier to delivering good care. Stephanie, a 55-year-old care aide with 2 years of experience at Green Lodge, elaborates on the situation at a LTRC facility where she was previously employed as a care aide:

> . . . it was never consistent in, like, closets were empty one day, they were full the next. So, you go to use a peri cloth that’s not there, you get a lot—Weee! Down

> the hallway to get one peri cloth to come all the way back and find out the pads aren’t there. They’d go all the way—like seriously nuts. **(Stephanie)**

Another participant reiterated this notion that, *“abundant supplies would definitely boost morale, 'cause I don’t have time at 7:00 at night to go wander around to every other wing in the building trying to find what I need. I mean, it takes me away from providing care!”* Like any occupation, care aides need the equipment that is necessary to complete the tasks at hand. Without the needed equipment, they are working in a situation that is destined to deliver insufficient and perhaps unsafe care to residents.

Another issue that participants brought up regularly was the issue of the inappropriate or unsupportive design of LTRC facilities. As previously mentioned, most participants interviewed had been employed at other LTRC facilities in the past, and many still picked up casual shifts at these sites. Participants discussed at length the frustration they felt when working in settings that were not conducive to facilitating good care. For example, Heather described the institutional LTRC facility where she had previously been employed and how the setting was not conducive to a good work environment or a good living environment for the residents:

> It was the lighting. It was everything about the place—grey walls, really dim lighting. Like, your eyes would just be like sore at the end of the shift. Really weird. It’s just bad energy. . . . It was really, really poorly designed, poorly built, cheaply made, and just a thrown together kind of thing. They didn’t care. They just want to get their people in there. Like, just get people. Get that pay check, that check coming in, right? Keep that money coming in. They didn’t give a shit about the people. It’s just dim[ly] lit. The care aides obviously do [care], that’s why we’re in this line of work. But the management just did not care about us at all. **(Heather)**

How Heather describes the previous LTRC facility where she worked sounds like how one would imagine a prison setting. She highlights her belief that it is apparent that those who oversaw designing the facility and building it did not have the residents’ or the staffs’ best interests in mind due to how dreary, uninviting, and poorly lit was.

Interestingly, there was a consensus among most participants that they would be able to deliver better care to residents and that residents would be safer if Green Lodge had a locked unit specifically for people living with dementia.

> I think it just comes down to a lot too, because everybody's just grouped together now with the residents. Like if you look way back, you'd have, like, your extended care wards and stuff. And then they had, like, the locked down dementia. Do you know what I mean? . . . We don't have that here, so everybody's just grouped in together. So you've got a real mixture, right? And you've got your residents that are total full care, that can't do anything for themselves, that are aggressive, that put the staff, the rest of the residents, at risk. So I think it's—My own personal is that there's not enough facilities for—like gero-psych and—really for progressed dementia people that just don't do well with the rush-rush of a general facility. . . . Like, they need a little extra TLC. You need to be able to go at a slower pace in order to do their care and not agitate them and set them off. They need a quieter setting. . . . And because the people who are cognitive don't understand and get mad at the residents who [are] sitting there yelling and screaming because they think there's something running across the floor, right? Do you know what I mean? **(Helen)**

It is clear through listening to Helen that she has put a lot of thought into how this facility could run better and how she believes she could deliver better care to her residents as well as keep herself and her co-workers safe. Another participant continues with this line of thinking in wishing there was a segregated unit for people with later stage dementia:

> I think this building is amazing, but the design is faulted. . . . Because we don't have a locked ward . . . where we could put aggressive or palliative, separate the wing, brighten one side up, keep the other side dull and calm, but that's just not the way we're designed. But it would probably, really work awesome. But then the answer is, "Who's going to work down that wing?" Nobody's going to volunteer. I know [laughs]. **(Sharon)**

Sharon sheds light on the fact that participants regularly discussed how those with dementia were the more challenging residents to care for. She speaks to a common belief held by participants that if residents with dementia were segregated from other residents, care aides would be able to deliver better care to both populations—those with and those without cognitive impairment.

The following section will reveal some ways in which care aides have chosen to deal with the emotional distress, bullying, and abuse they witness in their occupation as well as the stress of feeling unsupported in their role in LTRC.

7.2.4. Coping Mechanisms

The stress of working as a care aide in LTRC is evident from the previous sections. As one participant reported, *“I’ve got a very balanced life, but the stress here . . . If you’re not a strong person, you will just lose your marbles here.”* This notion that the sheer chronic and acute levels of stress found in the role of care aiding was enough to drive someone *“mad”* was repeated during many interviews. Due to the amount of pressure and moral distress that participants reported, they often discussed using various measures for coping with the moral distress and sheer pressure of working as a care aide in LTRC. These coping methods were not always positive strategies, and when enough rapport was built during the interviews some participants felt comfortable sharing what they did off shift to stay *“sane”* in LTRC. Some participants reported using alcohol as a coping mechanism to deal with the abuse and bullying they were witness to:

> I’m so glad I’m out of [the other facility I worked in]. It’s kind of healing for me to be talking about this because I haven’t talked to anybody about it. It actually gave me a bit of a headache . . . But it’s just like—yes, it’s good to get this off my chest . . . Because I was actually carrying rather a lot of guilt around for quitting . . . And I started drinking more just because I was so stressed, eh. That’s why I said I quit drinking, because I was actually drinking quite a bit. And it kept driving me to—I didn’t know how to handle this stuff, right? **(Stephanie)**

Others discuss their thoughts of self-harm and their concerns that previous mental health issues, such as extreme anxiety, would be triggered due to the bullying that they experienced in the workplace, as in the following case: *“It was very stressful. I have—I still have, like, some issues to this day. . . . I nearly started having panic attacks. I haven’t had a panic attack in 2 years. . . . I started getting, like, urges to self-harm, which is something that’s not been an issue since high school!”* This participant relates her experience of bullying in LTRC as similar to what she experienced in high school. And yet some participants discussed healthy ways to indulge in self-care: *“Sometimes, like, I was just holding it in and holding it in. And I’m like, yes, I just need to let this out. Sometimes, just a really calm, bubble bath and a good cry, just all-alone time, just let it out.”* Unfortunately, as is apparent in the coping methods presented, care aides never reported formal counselling as an option or method of coping. Often participants reported that they were not aware of what was covered by their own health benefits and, therefore, were not aware if counselling was covered. Most care aides interviewed self-reported not seeking professional psychological support after witnessing traumatic events. Regardless of how care aides choose to care for themselves, the issue is that bullying and abuse are evident in LTRC and that these situations negatively affect the care aides' ability to deliver good care to residents.

The following section will describe how participants reported perceiving how people in general society view the care aide role within LTRC.

7.3. Perceptions of How Society Views Care Aides

How one thinks his or her work is viewed by the public may have an impact on the satisfaction that the person receives from the work. The *party question* was helpful in assessing how care aides felt society perceives care aiding in LTRC. Participants were asked to imagine they were at a party and were meeting someone new. This new person would ask the participant the stereotypical *"what do you do"* question? Participants were asked to describe what they believe would be the general response from this new person based on their answer. Eleven participants answered this question. A total of eight responded that the new person would focus on the "pee and poop" aspect of the care aide role. Two respondents said that the new person would say "you are crazy."

The discouragement and frustration of being in an occupation that society either regards in a derogatory way or has no idea about is evident. For example, the following quote explains why one care aide would not choose this career again because of how constantly demoralized she feels in the role:

> I wouldn't choose this work again . . . Because after 30 years of working as a care aide, I feel like there is no respect in what we do, and in all we do we are belittled. **(Betty)**

After they shared their answers to the *party question,* participants would often share their ideas on how to change both the current state of their profession as well as awareness of LTRC in general. As one participant reported, *"I think it would be really cool to bring people through—more visits. And it will just give the residents a chance to see people, but it'll also give people a chance to see the residents.*" In this quote, there is an interesting comparison of what the care aide would like and what would be beneficial to the resident. The care aide feels that what she does is unknown to society.

Some care aides reported that society holds their occupation in high regard and appreciates what they do. As one care aide put it, *"[When people find out what I do] they always say, 'You know what? Kudos to you. It's the job that I could never do.' Yes, they always say 'It takes a special person to do the job that you do.'"* Even still, there is a dominant sense of society not knowing what the care aide role entails and constantly focusing on peri care, as seen in the following quote:

> [At a party, people would respond with] "I can't believe you can do that. There's no way I could do that." And then I'll say, "When you had a baby, how did you get your baby changed?" They say, "Well, well, yes, that's my baby." I'd say, "Well, … that's exactly what they are to me. But they're adult." . . . They can wrap their head around the crap and the pee. The pee and poop is like for—you know, and they're hypocritical because they do it every day themselves [laughs]. I mean, do you know what I'm saying? You care for yourself, right? . . . Yes, some people will stop for someone with a flat tire, the 100 people will go by. **(Sharon)**

How care aides described their identity in answering the *party question* was also enlightening in how they perceived how society views their role as care aides. As one participant reported: "*This isn't my identity. It's what I like doing, it's my passion—it's a part of me … this is just a part of who I am, a very small part, [but] there are so many facets to who I am.*" How this care aide perceived her identity is especially interesting when juxtaposed against other healthcare vocations, such are nursing. If someone chooses to be a nurse, there are generally not many stigmatizing barriers to the person taking on this profession (unless you are a male nurse, in which case that population is still disenfranchised and marginalized by the general public). The participant's description of her self-identity seems to in part reflect a stigma associated with the care aide role.

Even those who say they love their role as a care aide still shy away from broadcasting this as part of their identity, as is seen in the following quote:

"[People think it's] cool [that I am an activity assistant]. They don't like it [if I say I am a care aide]. They're like, "Oh." … If they know what it is. They say, "Oh, you're an … Ass wiper?" … Or a diaper changer." **(Patricia)**

This excerpt was taken from an interview with a care aide who had taken up more education to re-tool herself to become an activity assistant. This is an appealing, although costly, option for experienced care aides. This participant worked part time as a care aide as well as an activity assistant. She began her answer to the *party question* positively by saying that people know what she does and appreciate it. When I asked her to change her response from activity assistant to care aide, there was a dramatic shift in how she felt she would be perceived by this new acquaintance. The level of frustration and demoralization of working in an occupation that is unknown or unappreciated in society was apparent in some of the interviews. The quote above from Patricia highlights how sometimes care aides searched for an identity that is not care aiding.

Juxtaposing the previous section that outlined how care aides view their role as important with such negative feedback from others regarding their role, it can only be assumed that this would affect one's own sense of self-worth. Even within the LTRC setting, care aides are not viewed in a positive light. This is evident from the following excerpt from reflexive journaling:

> The hair dresser [at Green Lodge] is very opinionated and asked "why the heck would I want to interview [care aides]?" It seems everyone has an opinion on [care aides]. **(Field Notes 05.09.16)**

It is apparent that care aides view their role as both important and difficult. They also realize they are uniquely suited to accomplish this role. Despite this, while there are some exceptions, care aides generally feel they are invisible members of the healthcare team and are often only seen as "ass-wipers." Out of eleven participants who responded to the party question, two mentioned they believe society doesn't know what they do. The following is what Carolyn, a 36-year-old-woman from China with 4 years of experience as a care aide, shared as part of her response to the party question:

Carolyn: I'm not a social person. I don't go to a party.

Researcher: Okay, what do people—? Do you feel like people know what you do?

Carolyn: In Western culture, yes.

Researcher: Yes?

Carolyn: Yes.

Researcher: Okay, sweet.

Carolyn: Yes. ’Cause I work with a—Yes. Actually half and half.

Researcher: Half and half?

Carolyn: ’Cause, I—Yes, I heard a lot of people think that is still a dirty job. Like, you have to get your hands dirty . . . Like, you have to wash poop, you have to wash puke, you have to get puked on and everything, right? So it’s not a pleasant job. They always say, “Why don’t you go for a nursing job? You don’t have to deal with the pee and poop.”

Researcher: Don’t you still have to though, as a nurse?

Carolyn: Not in nursing homes. Not very often, unless they are willing to help, like, a lot of them, they do more medicine. The care aide will actually get their hands in the poop, right? So it’s kind of different. But like—it’s not—Still, like a physical job, not a very nice job, but a lot of them, again, they understand how meaningful their job actually is, like you made the best of—Like the end of their life, they want to go happy, right? . . . So, that’s—I got half and half. Some people really appreciate and understand. Some people say, “You shouldn’t do that job because it’s too physical.” “Watch your shoulder.” Like, “See, you’re damaging yourself, and blah, blah, blah.” Yes, so.

Researcher: Would you think you want to go and do, like, an LPN or RN or something?

Carolyn: No, I’ve come to do this job because I want to. . . . I really want to be with the people like that, like actually come cuddle with the people in bed. It’s not—they like it. Sometime—Sometime, just that little bit make a difference. Like when they’re crying, who doesn’t want to be hugged? Who doesn’t want to be cuddled, right? So you just, like—sometime, you just lie there with them for just that little five—it might not even be five minute. Probably 10 second, they know somebody care. They know somebody loves, so it’s different. It’s different.

Carolyn describes that it is the care aides who have the closest relationships with the residents. In this way, having a “cuddle” with the resident, washing “puke” dealing with “pee and poop” the care aide’s role is boiled down to its most rudimentary task-based duty. Carolyn highlights how, yes, that is a ‘*not a nice job’* or part of the job but then she compares this role on her own choosing for the relational aspects of this role, to help those in her care know that somebody cares, that somebody loves. She emphasizes that it is a "different" role from what over half the population in Western society thinks the role of a care aide is.

The following section will discuss the reported views of participants regarding the quality of their vocation and the direction in which it is headed in the near future.

7.3.1. The Perceived Bleak Future of Care Aides

Participants had a grim outlook on where the role of care aiding is heading. They reported being concerned with the quality of new care aides and their education and reflected on the gaps in their own education. As one care aide described, *"We're—[laughs], you know, care aides are being pumped out like freaking Twinkies, man!"* It was a common perception among participants that care aides were being pushed through the system without being screened or adequately prepared and trained for the realities of the occupation. Participants discussed their frustration regarding the perceived *"no-fail policy"* of care aide educational institutions. One participant stated, *"They pump them out. They pump out the courses and pumped out the paper loan. Everyone graduates."* Participants appeared to be distrusting of the motivations behind students choosing to go through the care aide education system. They discussed their concerns about the quality and quantity of individuals who are hired to be care aides and were greatly suspicious of the perceived dubious motivations of the school system, as seen in the following quote:

> [Care aide schools] are getting all students they wanted . . . Because they know that [this town is full of older adults], there's always been jobs for care aides and—always these students that will be enrolling. What they are not thinking about is when they graduate, will they be a good care aide? . . . Do they have the qualities in them that will make them a good care aide? Or is it just you're just thinking about your business, right? . . . And, well, first and foremost, they have to make sure that their instructors should mirror for them the qualities of a good care aide. **(Cynthia)**

Cynthia believes that the reason care aides are seemingly pushed through the education system is that there is a need for care aides in our aging population. Her mistrust is whether or not the schools understand the skills needed to deliver good care to residents in LTRC. Other participants reported similar perspectives: *"It doesn't matter if they're the* *nastiest person in the world. It doesn't matter if they're drunk. It doesn't matter if they're abusive. It doesn't matter if they don't give a crap. They get the job anyway because we need them. We need care aides."* If care aides, in general, believe that the quality of their profession overall is going down, how does this affect their current morale as well as their perceptions of the care delivered to residents?

It was not all negativity expressed by participants during interviews. As one care aide states, *"I really enjoy talking to people and socializing and I just seem to fit. I like giving care. I love all the interactions with the elderly; it's just they're very honest and real."* Some participants found themselves in their role and love it. Two participants discussed how they tried switching to different occupations but inevitably came back to LTRC. Jennie shared that she continues to come back to LTRC, even though there are difficulties:

> I was a care aide at 18 years old, 19 years old, but I haven't been doing it this whole time. I've got married, looked after my kids for about 8 years. And then I sort of got into home support, didn't like that. It was too slow. And then eventually, I got back into care aide, and then I went to the lab, and now I'm back to this. So I keep coming back [laughs]. Yes. **(Jennie)**

Another participant, John, reported that he realized his job is strenuous, both emotionally and physically, but that he just had to come back:

> I had at some point [thought] about getting out of [care aiding] . . . I had it because it's a tough job. Yes, we deal with a lot, you know, you're in these people's lives for quite a while. And you see a lot of things. And you can only take so much of it for so long sometimes. There's a high burnout rate. I thought a couple of years ago, maybe trying something different, but I couldn't—I left for like three months. And it wasn't anything for me. And I missed the job too much, so I had to come back. **(John)**

John, who has 16 years of experience as a care aide, speaks to how the role, although challenging in many ways, is ultimately a satisfying job. The care aides who participated in this study recognize the difficulties, frustrations, and the associated barriers, yet they reported missing their work when they were not doing it and being drawn back to it when they would leave.

7.4. Conclusion

This chapter reviewed the care aides' perceptions of those who appear to hold more power than they themselves have in the LTRC setting, including their views of the union, the management team, and the LPNs and RNs they work with. Care aides discussed their perceptions of LTRC and their role within it, and shared their intimate accounts of how they perceive their role is viewed by society and how it is starkly different from the reality of what they experience. The future of care aiding in LTRC does not appear to be a positive one if the care aides themselves continue to have a grim outlook of where the role of care aiding is heading. The following chapter will include a review of immerging issues that could be remedied to effect improvements in how care aides are trained, to improve how they perceive themselves and how they are perceived by society, and to increase their own voice in LTRC.

Chapter 8. Discussion and Conclusion

This thesis presents a collective representation of care aides' experiences working within LTRC, including with respect to (i) training; (ii) entry into LTRC; (iii) relationships with others in LTRC; and (iv) their perceptions of the barriers and facilitators to delivering care to their residents. The first chapters presented a succinct review of the existing literature pertaining to care aiding in LTRC and built a case for why there is a dire need for exploring the experiences and perceptions of care aides in LTRC (Chapter 2). The next chapter discussed the methodology that was implemented and that guided the creation of the research study design, data collection, and analysis (Chapter 3). The results of the study were then discussed at length in four detailed chapters: Part I, care aides initial exposure to care aiding, their education and training, and their entry into LTRC (Chapter 4); Part II, care aide perceptions of the other participants within LTRC (Chapter 5); Part III, the challenges that care aides experienced while being employed in their role (Chapter 6); and Part IV, the perceptions of power and powerlessness that care aides have based on their occupation, both in the LTRC environment and within the greater society.

This chapter will begin with the implications of the study findings, including locating them within the broader context of the published literature as well as current policies that affect care aide education and employment in LTRC. Based on the results of this study, a list of emerging issues will be then discussed, including (i) preparing care aides for the realities of their role in LTRC; (ii) supporting care aides during their role in LTRC; and (iii) changing policy implications to better support the changing needs of a growing occupation as well as facilitate a re-branding of the care aide role in society by including them in the global movement for dementia friendly communities. This chapter will conclude with a review of the limitations of this study and suggestions for future research.

8.1. Locating the Research

To highlight the value of this thesis, the findings must be held alongside the greater body of knowledge surrounding care aides in LTRC. Locating this study alongside the current published literature includes (i) confirming, (iii) elaborating, (iii) critiquing, and (iv) contesting this research. Each of these four pillars will be discussed in the following sections.

(i) Confirmation

There is an agreement in the literature that care aides are an understudied workforce (Caspar, Ratner, Phinney, & MacKinnon, 2016; Mallidou, Cummings, Schalm, & Estabrooks, 2013; Scales, Bailey, Middleton, & Schneider, 2017; Squires et al., 2015). Very little is understood about care aides regarding fairly basic information, including the nature of their preparation, work motivations, attitudes toward their work, and aspirations (Berta, 2013). Weis et al. (2015) found that the understanding and cooperation of family members was crucial to the care aides and that many care aides left their occupation in LTRC due to discouragement by their family members who dislike the low social status, pay, and prestige (i.e., “losing face”). Although it was beyond the scope of this study to review why care aides left their role in LTRC, participants did speak about the importance of their families being supportive of their work and the frustration they felt when their families were not supportive of their care aiding occupation.

A study conducted by Woolrych and Sixsmith (2013) examined the experiences of formal carers in the United Kingdom, the equivalent of care aides in Canada, working with an integrated dementia service provider called CareConcepts. They identified the challenges of providing flexible and responsive service provisions for those living with dementia within this integrated care setting. In this study, the formal carers considered themselves specialists care providers (given the unique challenges of supporting those living with dementia) who required three different types of knowledge: (i) propositional knowledge developed through formal training; (ii) “onsite” training obtained through experiences; and (iii) learning from others working in the field by sharing experiences. The care aides who participated in this study also reported similar conclusions regarding their knowledge of dementia and the residents they care for. As discussed in the results section of this thesis, care aides stressed the need and importance of the following: (i) appropriate education prior to entering LTRC; (ii) being mentored once inside LTRC; and (iii) the value of personal experience, or tacit knowledge, to benefit the care aiding role.

This thesis confirms that there is a paucity of opportunities in LTRC for care staff to gather as a cohesive group. The care aides in the study from Woolrych and Sixsmith (2013) reported that although they engaged in informal dialogue while “on the job,” they found that there were limited opportunities for them to come together as a group to discuss problematic cases and solutions with fellow care aides. The participants in this thesis also reported a lack of opportunities to collectively discuss those they deliver care to. Along similar lines, they asked for opportunities to build team cohesion with one another and felt that with greater cohesion there would be an increase in collaboration and “team spirit” that would benefit the care delivered to residents as well as the care aides’ collective morale.

The frustration of care aides not having the ability to formally record has been reported in the literature and has also been confirmed in this study. Woolrych and Sixsmith (2013) found that staff continuity was an important issue, with carers working across day care outreach but not across respite. Because of this, information that would have proven valuable to the delivery of patient care was not freely shared among carers because of different health and social care record keeping regulations, which ultimately negatively impacted care delivery. Staff in this study reported that “continuity of care” facilitated their ability to monitor everyone receiving care throughout their care journey, which enabled the care aides to collate and share knowledge of the individual. Care staff in this study also reported that the bureaucratic social care service system did not allow them to use discretion in their care delivery nor listened to their concerns, which created an atmosphere of carers feeling undervalued in their work and relatively powerless in their ability to improve the lives of the service users, the residents, they were attempting to provide care to. In this thesis, similar issues were found regarding care aides being repeatedly reminded that they are the *“eyes and ears”* of the LTRC setting, yet they had no formal venue in which to record or confidentially report their concerns. This issue was presented in depth in Part III of the results in the section titled, “Screaming into the Void.” Care aides desperately wanted to make positive changes in the lives of their residents, but without having the ability to express their concerns or requests, they felt their hands were tied and they were powerless to effect large-scale, systemic, and positive changes.

The rates of resident-to-care aide aggression that has been documented in the literature have also been confirmed in this study. It has been well recorded that aggression from LTRC residents toward care aides during personal care is a significant problem (Zeller et al., 2009). It has also been reported that nearly half of Canadian care aides in LTRC experience violence daily or near daily (Daly, Banerjee, Armstrong, Armstrong, & Szebehely, 2011). This thesis confirms these findings that aggression toward care aides in the LTRC setting is rampant. Unfortunately, Castle's (2012) impression is that understanding and interventions within LTRC related to abuse have not progressed much beyond the school yard mentality in some nursing homes. Participants in this study appear to agree, given their responses to the atmosphere created by abusive acts. Nearly each of the 31 participants spoke of being on the receiving end of physical aggression from residents on a regular basis. Participants spoke to this being an unfortunate but accepted "norm" in their occupation in LTRC.

(ii) Elaboration

Findings of multiple studies support the theory that care aides compensate for negative aspects of their profession with the positive experiences of caregiving and learning new skills (Stacey, 2005; Rakovski & Price-Glynn, 2010). Learning new skills, doing challenging work, having high workplace morale, and caring for others are the key components that have been reported to make care aides prideful about their work. The results of this thesis add to this conclusion by reinforcing that care aides compensate for the negative aspects of their work not only through the aforementioned venues but also through the notion that that they are part of an elite group of individuals who are able to excel in the care aide role. As discussed in Chapter 7, there was a consensus among care aides in this study that they believe the following: care aides have an important job and they are uniquely suited to do this job successfully. Although care aides do not have the same knowledge and expertise as skilled nurses, they recognize that the work they do does require a specific skill set and level of empathy and patience in order to meet the task-based and relational care needs of their residents. Similar to how Woolrych and Sixsmith (2013) found that their care staff considered themselves to be specialists care, providers, the participants in this study perceived themselves to be the experts regarding their residents' wants and needs.

(iii) Critiquing

Rakovski & Price-Glynn (2010) found that care aides are more positive about their work than the literature suggests. Some of the sources of job satisfaction for care aides that they identified include learning new and challenging skills, workplace morale, valuing the importance of their work, the motivation of caring for others, and organizational support for emotional labor. Although participants in this study did consistently report feeling satisfied with their role in LTRC and with the care they delivered to residents, it must be emphasized that the negative aspects of care aiding in LTRC were found to be just as true in this study as the literature suggests and perhaps even more so. The degree of bullying, abuse, injury, and powerlessness consistently overshadowed the positive components of the care aide role in LTRC.

Weis et al. (2015) found that most care aides expressed positive aspects of their work experiences, such as companionship, happiness, trust, and achievement. Also, most care aides reported that caring for residents was a process of offering love that gave the care aides a sense of happiness. The care aides were happy to have companionship, love, and praise and considered their work to be an important process of offering love. This thesis also found that participants reported many positive aspects of their work; however, unlike Weis et al., (2015), trust was not an overarching positive theme. The participants in this study indicated a lack of trust in management, the union, their nurses, each other, and research experience. Although participants would report trusting specific individuals within LTRC, the lack of trust held within this population was evident from the results of this thesis as well as from the research process.

Dissimilar to Woolrych & Sixsmith (2013) in how participants felt that doors created a physical barrier that prevented the use of shared space and inhibited their service delivery, participants in this study requested more physical barriers and greater segregation between residents with later stage dementia and those without dementia. In this study, formal carers discussed issues relating to the physical environment and staffing organization across the different care domains, which participants perceived were barriers to their seamless delivery of care. Observations conducted in this study noted that there were physical barriers that prevented the day care and respite center from working closely together. Woolrych & Sixsmith (2013) noted the absence of open doors and free access to the services that prevented the use of shared space, with little opportunity for service users' interactions. In the current study, similar issues with the physical environment were also perceived by care aides to be a barrier to care delivery. One of the interesting revelations is that despite the recent movement to "unlock the doors" to segregated dementia care areas in LTRC (Power, 2017), the majority of the participants in this study believed that if only they had a segregated and locked dementia care unit, they would be able to deliver better care to residents.

(iv) Contesting

Research with nonprofessional workers, such as care aides, has highlighted that they often feel vulnerable in their employment and, therefore, may be less likely to speak out (Sims-Gould et al., 2010). Although this was also found to be the case in this study, system communication barriers (such as not being allowed to write their own reports and having to go through the head nurse to report) may also be seen as a reason for the limited amount of "speaking out" that they do. In fact, the care aides in this study continually spoke out, but they reported that their verbal requests and concerns often fell on deaf ears. The outspoken nature of the care aides at Green Lodge, in comparison to other care aides in LTRC, may be due partially to the fact that most of these care aides were Caucasian whereas in most LTRC settings the majority of care aides are migrant women and visible minorities.

Scales et al. (2017) examined the role of care aides in dementia care settings in the United Kingdom with particular attention paid to the relations of power that define their experiences and possibilities for action. Interestingly, this study found that care aides challenged their marginalization through the careful maintenance of a strong collective identity. The participants in this thesis did not express this collective identity to the extent that Scales et al. (2017) discuss, although the participants in this thesis recognized that *"only care aides can really get what it's like to be a care aide,"* as they did in the Scales study; the participants in this thesis did not, however, have a strong collective identity. Rather, participants in this study discussed at length the "within group" politics and workplace bullying that occurred among the care aides.

One reason why the Scales et al. (2017) results centered around the care aides' strong collective identity could be that Scales took the care aide training and entered the LTRC settings as "one of them." (Note: this training consisted of 4 days of education compared to 6 months of education in Canada.) In contrast, for this current study, I entered the LTRC setting as a researcher and maintained that status the entire time. The following section will review the four overarching issues that emerged in relation to improving the care aide role and delivery of care in LTRC.

8.2. Reflexive Analysis of Research Experience

The reflexive analysis of the research experience is divided into two sections, first a discussion of the research experience itself and second a reflection of my advocacy and consulting work that occurred congruently with data collection and the writing process of this doctoral thesis.

Research Experience

Exploring the role and perspective of care aides, arguably a disenfranchised and vulnerable population, was a unique and eye-opening experience both as a researcher and as a dementia advocate. As previously discussed, the care aides were often not trusting of the interview experience and great lengths had to be taken to modify the experience to make it as comfortable as possible for them, as well as to build enough rapport to collect the necessary data to answer my research questions. My original research guide was the Multiple Sorting Technique (MST) developed by Sixsmith and Sixsmith (1987), an empirical phenomenologist tool for investigating conceptual systems. The main principle that underlies this interview technique is that people think about and deal with the world through categorization. Uncovering the natural meaning categories is the main goal of the MST (Sixsmith & Sixsmith, 1987). This interview technique provides a framework for self-analysis with its main objective simply being to help people analyze their everyday understanding of things. MST works together with the interviewee and the interviewer to get behind the natural attitude of taking things for granted (Sixsmith & Sixsmith, 1987). The main objective of using MST as an interview technique is to sort elements into categories or groups based on a single criterion at a time. MST was chosen as the appropriate method for examining care aides' experiences and perceptions of their role in LTRC because it allowed the interviewer to work with the participants to critically examine their perceptions and experiences. The MST required participants to think through and analyze their decisions using examples from the MST to conceptualize the questions being asked. As previously stated in Chapter 2, Erving Goffman (1962) discussed how those who work in Total Institutions, such as the LTRC environment, are often institutionalized themselves. The MST was thought to allow care aides to access their underlying experiences and perceptions that may not otherwise have been easy for some care aides to access because of the powerlessness they may feel to do anything to change their situation. This method was also thought to work as a starting point in discussions to examine what the care aides' perceptions were regarding the barriers and facilitators to their care delivery care in LTRC. To my surprise, this tool served as a barrier to conversations with care aides because of the underlying assumptions that were not met that would have allowed for this to be a successful research tool with this population, as can be seen in the following excerpt from my field notes:

> I found this interview very interesting because this was the first time that a participant openly asked me *"why are we doing this?"* with the MST. I was asking her for names of co-workers. Upon further reflection, I see that I would also be [suspicious] about some random researcher meeting me in the fanciest room in the facility, with coffee and cookies and fancy china. And I blatantly say I am trying to understand how to make the [care aide] role better/more respected by society, etc., with my study and then I ask her for names. It could have easily looked to her in her eyes that I was trying to get her to be a whistle-blower on her co-workers. We couldn't even get to the sorting of the MST. I don't like using the MST when I can have a normal, open conversation with people. It's weird enough that a researcher is talking with them, let alone they want them to organize cards—it's too [much like what they may perceive a psychiatrist interview] to be like … Will the MST work for RCA interviews? **(Field Notes 09.11.2015)**

There appeared to be three unmet assumptions that would have allowed this method to be used with this population: (i) assumption of trust; (ii) assumption of time; and (iii) assumption of research exposure.

Regarding the first assumption of trust, the participants, unbeknownst to the researcher at the beginning of this study, generally do not trust those in positions of perceived higher power than themselves within the LTRC environment. They reported a lack of trust to each other, management, and even their union. It was also apparent that participants often did not trust the researcher or the research experience. To conduct the MST with care aides, there needed to be an established level of trust that what they discussed during the interview, about their personal information, their residents, or their colleagues, would stay confidential. It is incredibly difficult to conduct an empirical phenomenological interview when the individual you are attempting to interview believes his or her job security may be at risk due to something he or she may say during the interview. Another issue with the assumption of trust was that care aides were extremely concerned about confidentiality regarding their residents and colleagues. Because of this, the researcher and participants had to continue to use pseudonyms when it came to the sorting for these topics. Pseudonyms quickly became a barrier to conversation, as seen in the following excerpt from the field notes:

> I used the MST with Linda as a way into getting her to talk about her fellow care aide. The problem is that there is so much concern over confidentiality and anonymity it is like pulling teeth trying to get her to name people, and when she does name them she uses “aliases,” and after half a dozen aliases the actual sorting task is a nightmare because I have to constantly remind her who is who and it takes away from the [expletive] interview! The same is true with residents—care aides do not want to talk about the residents or other staff members in specifics and it’s too dodgy for me to ask them! It’s not fair for me to put them on the spot like this when there is already a power differential between me and them, and I don’t want them to feel exploited. **(Field Notes 02.11.16)**

The second assumption is that of time. The MST takes a lengthy amount of time and it cannot be rushed. Care aides in LTRC do not have the luxury of time. Often when care aides agreed to participate in this study, it was under the pretense that there would be an extra care aide booked to cover them when they were off shift. Unfortunately, due to the sheer amount of care aides “calling in sick,” this was often not the case. The following quote highlights this:

> **Researcher:** You were just telling me you had to be pulled off shift for this interview. That’s a very important note. Can you tell me what we just discussed about how many residents are on your floor right now?
>
> **Helen:** On the wing I’m working on today, there [are] 22 residents. And so now, the other two care aides I’ve left there are responsible for all 22 while I’m off the floor [for this interview].

In this instance, Helen did not have the opportunity to have a lengthy interview during which the nuances of the MST interview could be explained and the process of discussing and sorting her residents, care tasks, or co-workers could flow naturally. It was far less of a barrier for both the care aides and the researcher instead to engage in a conversational, semi-structured interview.

The third assumption is that the participants have been exposed to research in some previous setting. Prior to beginning an interview, one of the first questions participants were asked was if they have ever participated in research. Almost no one had (by the time I had completed the 27th interview, two had said yes). Because of this, participants were often very hesitant to converse. Rapport was generally built through the researcher's humor or knowledge of Old Town, Green Lodge, and care aiding. Rapport was incredibly difficult to build when pieces of paper for the MST were revealed and participants were then asked questions about their role in LTRC. One field note recorded the following experience (found on page 222) where a participant openly asked "*Why are we doing this?*" with regard to the MST. In this field note, I come to the realization that this interview technique, in the eyes of the care aides, made me look like a psychiatrist or counselor who was trying to get at their underlying feelings, and it was apparent that the care aides wanted nothing to do with this. Participants, due to their lack of exposure to research, were often incredibly nervous about being interviewed. The following excerpt from field notes outlines this:

> I could tell she was nervous because it took her four times to get the date correct on the consent form. She also asked me a number of questions before the recorder went on that made me think this was her first time being interviewed for a research study. I asked her and she told me it was her first time. I took extra time to explain why I have a voice recorder and what I will be asking and why I am doing this research. I did this all before I turned on the recorder. **(Field Notes 02.11.16)**

Another field note outlines similar structural barriers in using the MST to interview care aides:

> I used the MST with Patricia to get to understand her residents better. Again, she wanted aliases for her residents (makes sense, of course she wants anonymity). Again, we could only do three sorts and then all the aliases got too confusing and it was easier just to continue with our natural conversation. **(Field Notes 02.12.16)**

The MST was not allowing me and the care aides to converse in a natural way. As such, the reality of the care aides' experiences and the perceptions they held of their role within LTRC were not being discussed during interviews. Shortly after the interview of 02.12.16, and after consulting with my supervisor and committee for their guidance, I stopped using the MST altogether and focused on a more conversational interview guide (Appendix A: Interview Guide).

The following section discusses my career as a dementia advocate that occurred congruent with the writing of this doctoral thesis.

Dementia Advocacy

Throughout the entirety of working on my doctoral degree, I have participated in dementia related advocacy endeavors—provincially, nationally, and internationally. I believe that one of reasons this thesis is focused so heavily on the perspectives of care aides in LTRC is that often through my advocacy work I have seen how the voices of care aides, the true backbone of insitutional dementia care, are left unheard and unnoticed by the change makers at the top with the decision making power. This is my journey, especially in relation to my advocacy work and my Ph.D. studies as well as to importance of my work with care aides in LTRC. My journey as a dementia advocate began long before I started working on my doctoral degree. As an adolescent, I found myself often in trouble at an early age, committing petty crimes and struggling to remain in school. The final time I was arrested, the local First Nations Band intervened on my behalf and instead of going to juvenile court, I was sentenced to complete several hundred hours of community service in local long-term residential care homes, often alongside my mother. Through this experience, I witnessed how both the staff and the residents with dementia in long-term residential care where abused, disempowered, and hurting. It is from these experiences and relationships that my passion and internal drive to be able to create positive change in the lives of those impacted by dementia has grown. Since then I have devoted my life to making the situation better for both those living with dementia and those supporting those living with dementia.

Both my research and my dementia advocacy projects stand alongside over a decade of various university and industry led research projects related to dementia. I have successfully translated research evidence into effective policy and practice to positively affect the lives of those supporting and those living with dementia. I see this doctoral thesis as a logical evolution in my career and as the next step towards further maturation of my training as a researcher and advocate. My achievements in dementia advocacy and research and leadership can be summarized in three outputs: my work as a founding member of the World Young Leaders in Dementia (WYLD), my work as founding member of the Dementia Friendly Old Town initiative and my continual involvement with progressive academic and industry research in dementia care.

WYLD emerged from a series of legacy meetings following the 2013 G8 Dementia Summit. The U.K. Science & Innovation Network invited emerging leaders working in diverse fields of dementia to meet at events held in Ottawa, Tokyo, Washington, D.C., and London (GOV.UK, 2014). WYLD developed a draft set of proposals to present at WHO's First Ministerial Conference on Global Action Against Dementia in March 2015. This process sparked a number of new research collaborations and the creation of the WYLD network.

On a local level, I have been helping Old Town establish itself as one of Canada's most dementia friendly communities. I have been volunteering with the town council since the summer of 2015, when data collection for this thesis began, to assist them in moving forward with dementia inclusivity. I have organized two town hall meetings on dementia friendly communities, both with international speakers, including Elena and Nico Bins from Dementia Friendly Bruges, Belgium. I worked on these dementia friendly community projects and data collection, which helped combine the two projects to bolster both my involvement in the community (in assessing the community situation) as well as the care aides' involvement, so that I was not perceived to be a transient (instead, I was apart of their community too).

In addition to my advocacy work and working on my doctoral degree, I have been employed in various aging- and dementia-focused consulting positions. In this role, I oversee the evaluation of dementia inclusion and dementia-related stigma in the context of retirement communities. My responsibilities in these communities also include the development of an interactive educational intervention to promote awareness about social inclusion and the reduction of stigma related to people living with dementia. I am a firm believer in participatory action research initiatives and posit that the true "dementia experts" are those living with dementia (Power, 2017). As such, all aspects of this industry focused study, involved the participation and guidance of individuals who are currently living with dementia, including the expertise of the Ontario Dementia Advisory Group (www.odag.ca).

Due to my longstanding role as a dementia advocate and researcher, I was invited to Canada's first National Dementia Conference, which was the initial step in developing Canada's National Dementia Strategy. I also serve as one of the founding members for Canada's Dementia Action Alliance, a group comprised of people living with dementia and their care partners, as well as advocates and researchers—all of whom are focused on helping push Canada forward in supporting the human rights of those living with dementia. As a dementia advocate, I am aware of the global increase in those living with dementia and the strains this places on families as well as on the LTRC workforce. I will continue to push my own boundaries and societies' boundaries regarding how we can support and care for those living with dementia and those caring and supporting people living with dementia- especially the care aides in LTRC.

8.3. Emergent Issues for Improving Practice

Government Investment

In January 2010, British Columbia became the first province in Canada to implement a registry for care aides and community health workers (also known as HCAs) with a mandate to protect the public. BC has arguably the most successful care aide registry in Canada. This is due to both the union and public sector employers insisting that care aides register with the care aide registry. Currently, there are approximately 31'400 care aides registered on the BC Care Aide and Community Health Worker Registry. The registry process is voluntary and free of charge and has an automated process that prompts care aides by email to verify their account on a yearly basis. Approximately 20'000 care aides are in public care settings and the other 11'400 are in private care settings. On average, public care pays better than private and there is more job security. If Canada had a national care aide registry, the voice and impact of care aides would be better understood.

The BC Province is investing $500 million over the next 4 years, through 2022, as part of a Ministry of Health action plan to improve care for seniors across the system, including by increasing direct-care hours for seniors in residential care (Health, 2017). Over the next 4 years, year-over-year funding is predicted to increases from the Ministry of Health, which will enable each health authority to reach a consistent average of 3.36 direct-care hours per resident day across both publicly administered and contracted residential care facilities (Health, 2017). Due to this commitment to an increase in spending, the time is right for changes to be implemented in the way care aides are educated, regulated, and supported within LTRC.

The following is a list of emergent issues that must be attended to for improving and facilitating the delivery of care in LTRC by care aides to residents. These issues were influenced by the data that was collected during interviews, naturalistic observations, and reflexive journaling completed during this study, as well as by the literature, the interpretations of the researcher, and input from key stakeholders. I also had phone conversations with representatives from the Ontario Personal Support Worker Association (June 2017), British Columbia Care Aide Association (May 2017), and the Health Association of Nova Scotia (June 2017). During these conversations, these recommendations for improving practice were reviewed. The following issues may be summarized in three overarching topics: (i) regulating education and training; (ii) allowing for autonomy as part of the care aide role; and (iii) improving morale by improving societal perceptions by bringing care aides into the dementia inclusive and friendly movement.

8.3.1. Preparing for the Realities of the Role

Most participants in this study expressed that they felt they were not adequately prepared for the role of care aiding in LTRC. The following sections outline three key suggestions based on the findings of this study that relate to preparing care aides during their education and training for the realities of the care aide role in LTRC.

Regulate Education and Training

The role of care aides has changed drastically over time. Some studies report that as recently as a decade ago, the role of care aides was predominantly supportive and involved assistance with daily living activities, such as bathing, dressing, meal preparation, and other light household tasks (Berta, 2013). Currently, care aides in LTRC have increasingly complex clients to care for. Due to these changes, care aides are now routinely being asked to complete tasks that they previously were not asked to do and have not been formally trained to complete. This “role expansion” among care aides has prompted calls for standardized approaches to education, training, and supervision (Berta, 2013).

In Canada, national standards have yet to be implemented for care aide education. A national standardization of education policy for care aides would facilitate two important factors that participants discussed regarding their education and training: (i) the educators, and (ii) scope of practice. In this study participants, discussed the frustration they felt toward their teachers who they did not feel were in touch with the reality of LTRC. Participants repeatedly discussed the fact that there was no comprehensive understanding as to what their scope of practice was. If there was standardization that included a national exam for care aide qualification of what care aides need to know in order to graduate and be employed, both employers and educators would be held accountable. Also, there would be predictable outcomes that could be measured for future research and perhaps this occupation would become more recognized and esteemed in society. One province that has managed to take things into their own hands is Nova Scotia, where a standardized scope of practice, education curriculum, and graduating exam for all care aides has been in place since 2000. This level of standardization allows for employers to know exactly what to expect of care aides and for the care aides to be better prepared for the realities of their role in LTRC.

Screening Prior to Education

Participants in this study spoke to their belief that a good care aide is born with “empathy and patience” and that these are not skills that can be acquired during education and training. These two traits were discussed by participants as being essential to delivering good care in LTRC. Participants also spoke, at length, to the dangers of working alongside care aides who were not patient or empathetic, either with their residents or with their fellow care aides. They described these individuals as serious risks to the well-being of the residents as well as barriers to their fellow care aides being able to deliver good care.

When asked what could be done to ensure that the most appropriate individuals are hired as care aides in LTRC, participants were adamant that the process must begin prior to someone even entering the educational setting. On multiple occasions participants spoke to creating a screening process for care aide schools whereby even before accepting individuals into the program they would be evaluated to detect if they have the emotional capacity, along with the physical and intellectual capacity, to be a good care aide.

Trauma and End-of-Life Education and Support

During interviews, care aides often brought up the fact that they did not feel prepared for the reality of the care aide role in relation to the often-graphic end-of-life situations they witness in LTRC. Approximately 75% of deaths in Western societies occur in institutions, primarily hospitals and LTRC facilities (Timmermans, 2010; Barwich, 2017), and some have recently asserted that LTRC may soon need to be re-classified as “Palliative Care Units for the Aged” (Schulz, 2011). In light of this, care aides need to be prepared during education for the realities of the often-graphic and upsetting situations they may find themselves in. Just as first responders are educated on these issues, so should care aides. Their education and training should shed light on the fact that they should be prepared to view scenes that may be violent and disturbing, as well as allow care aides to discuss and explore positive self-care and grieving venues to mitigate the negative effects that these events may have on their well-being.

In Part II of the finding (Chapter 6), participants spoke about a “dance” that care aides were taught in school. Participants described this dance as learning how to care for their residents but not getting emotionally involved in the process. Based on the accounts shared by the more experienced participants in this study, it is apparent that the dance is not working and that it is causing undue emotional harm to participants. Participants spoke to their being a paucity of approved and supported ways to grief over the loss of residents. One recommendation is if care aides were encouraged to grieve and mourn in healthier ways, perhaps less sick days would accrue and fewer injuries would occur on shift. Also, care aides need to be prepared and trained for extreme horrific cases (e.g., Jane having to mop bloody walls and a floor after a resident with blood clots became ill). They need to be prepared that in this occupation they may witness some traumatic events and here is what to do during the event, here are the resources to use, and this is who you can to talk. Also, care aides must be trained and re-trained about the dangers of infectious diseases. They deal with body fluid often and they must be kept informed of best practices to keep them safe and prevent the transfer of infections.

8.3.2. During the Role: Autonomy Needed

In British Columbia, care aide education takes an average of 29 weeks. The Health Care Assistant Program is designed to provide students with opportunities to develop the knowledge, skills, and attitudes necessary to function effectively as caregivers as well as respected members of the healthcare team, both in the community and within facility settings. Under the direction and supervision of a health professional, graduates provide person-centred care aimed at promoting and maintaining the physical, emotional, cognitive, and social well-being of clients/residents. Upon completion of the program, graduates are said to be prepared to work in a variety of settings, including acute care, home support, adult day care, assisted living, and LTRC (Health Care Assistant Program Provincial Curriculum Guide, 2015). Due to the complex needs that residents have in LTRC, as well as the ever-changing landscape within LTRC, care aides need to have access to continual education. Participants would often bring up how they would gain education on their own time to better equip themselves for delivering good care to their residents.

Make Them a Member of the Team: Allow for Documentation

Care aides provide a bridge between housekeeping, residents intimate daily care, and the nursing staff. They provide the most task-based and relational care in the LTRC setting. More needs to be done to facilitate team cohesion and communication among members of the care aide team as well as between members of the care aide team and members of the healthcare and support team. Suggestions for improving team cohesion and communication centre around the care aides' ability to document what they see regarding the care and support they provide to their residents as well as their interactions with other staff members. By allowing care aides the ability to document will facilitate them having a stronger voice and overall presence in discussions relating to resident care.

Implement a Duty to Report

Armstrong (2016) makes a poignant analogy to describe the importance of giving care aides autonomy in LTRC: *"To make a street safe, you put a veranda on every house, facing the street. This will make the street safer than any amount of police presence. To make everyone safe, you make everyone a part of the 'team.' The same thing is true in [LTRC]—you need to get the whole team involved to ensure the safety of both the team and the residents."* The findings from this study are in agreement with Armstrong (2016); care aides must be brought further into the healthcare team and be offered the ability to report.

A review by Boye and Yan (2016) summarizes the available literature on abuse of older persons with dementia. The results of this review emphasize the urgent need to create and implement effective intervention protocol specific to elder abuse among residents living with dementia within LTRC. They advocate for the creation of both indirect and direct intervention measures (Boye & Yan, 2016). Direct intervention may take the form of legal measures, such as physically removing the abused resident from an abusive situation, although this may not be appropriate or feasible. Indirect intervention may include the use of mediation or support services. Boye and Yan (2016) also suggest that in order to minimize self-report biases in single reporters, reports by other informers should be taken as validation checks. Registered nurses have a "duty to report," but currently care aides do not have this. Care aides need to have written within their scope of practice a duty to report incidences of improper care, abuse, bullying, or neglect. Care aides need to be given a safe venue to report their concerns. Along the same lines of duty to report, the issue of communication between care aides as well as other levels of the healthcare team was evident from the results of this study. Venues for effective communication between all levels of the healthcare team, including management and housekeeping, must be put in place to facilitate the delivery of safe and effective care, as well as the maintenance of a safe work environment.

Recognizing Relational Care as Important as Task-Based Care

By allowing room in the care aides' scope of practice for relational care, care aides will be granted greater autonomy over the decisions of care for their residents.

There are many suggestions to facilitate increasing care aides' autonomy over their residents' complete care, including but not limited to: (i) implementing fixed assignments with residents; (ii) including the duty to report in the care aide scope of practice; and (iii) inviting care aides to the table. These will be discussed in the following section.

Evidence shows that when care aides have sufficient time to work with residents, there are benefits associated with care aide performance and excellence, comprehensive care, quality of outcomes (e.g., reductions in pressure ulcers, urinary tract infections, and falls), resident quality of life, and cost savings, as well as with the transformation of organizational culture (Mallidou et al., 2013). Research has also shown that care aides who spent enough time and had permanent (instead of rotating) assignments with certain residents were more likely to be satisfied with their jobs (Bishop, Squillace, Meagher, Anderson, & Wiener, 2009).

An issue that was brought up repeatedly by participants was the difficulty in delivering care to residents with whom they were unfamiliar; they do not know their likes or dislikes, wants or needs. Rotating staff may be thought of as a form of institutional oppression for both the resident and the care aide. The well-being of the resident and care aide, as well as the quality of care delivered, may increase when care aides have fixed resident assignments. This will allow a care aide to get to know a resident over a long period of time as well as facilitate the resident's knowledge of and trust for the care aide. Participants in this thesis have made it clear that care aides would value autonomy over their residents. One remedy to this situation could be permanent full- and part-time care aides having set residents whom they care for. The autonomy that cares aides desire would be better facilitated by allowing them to foster relationships with their residents to the highest degree possible through the privilege and honor of being their residents' "primary" care aide. One suggestion is to even give care aides the title of *"primary care aide"* for their residents, which may allow prestige and ownership of their residents' care delivery.

Another solution is to invite care aides to the table to be a part of discussions and decisions that affect them and their residents. I have attended a number of care conferences where the entire focus of the event is improving resident care outcomes, yet there is not a care aide in sight. One suggestion regarding how to empower care aides is to invite them to the table. Just like those living with dementia, invite care aides to these conferences, discussions and high power meetings where decisions regarding dementia care are made. And not just *any* care aide, not just *anyone*; the person needs to be empowered enough to speak on behalf of others, champions for the care aides.

Technology and the Future of Care Aiding

It is important to recognize the future role technology will have in LTRC. From the results of this thesis, it is apparent that the participants in this study often identify themselves as professional carers for their residents, yet they are treated as nonprofessionals and frequently feel they are voiceless and without a means of reporting or autonomy over their residents' care decisions. In reality, care aides in LTRC may be thought of as a middle ground between members of the healthcare team and members of the housekeeping team, as service and hospitality members. Perhaps through the use of technology these barriers may be remedied.

The answer may not be that technologies such as robotics may deliver relational care to residents with dementia, although this is being put into practice (e.g., Pepper, the semi-humanoid robot designed to be able to communicate with humans). Instead, robotics can perhaps also support care aides by supplementing the task-based care they provide. In this way, the care aides can focus on the human–human relational care they are also in charge of delivering. In the coming future, it is predicted that many of the task-based aspects of dementia care are going to be conducted by robots (Hebesberger, Koertner, Gisinger, & Pripfl, 2017; Huschilt & Clune, 2012;). It would be wise for society to focus now on this shift in the role of care aides to appreciate the rational aspect since in the near future robotics may slowly start to take over small tasks in the LTRC setting. Currently it may just be washing machines, dishwashers, and tubs—what about in the future, when a robot may be delivering care and taking over different roles that care aides once filled?

Another form of technology that may be implemented and seen by society as a little less intrusive is electronic health recording (EHR). EHR now have the capacity to develop novel methods to identify late-stage dementia patients for palliative care research and practice (Ernecoff, Wessell, Gabriel, Carey, & Hanson, 2018). Through the use of EHR, care aides would have the ability to track and plan their shifts, further understand their residents' needs and preferences, document activities of daily living (ADLs), manage medication observation and administration, and communicate with co-workers during and across shifts. These capabilities may be delivered through a mobile phone application, which would allow users to connect to the EHR at any time. They will have access to all pertinent information throughout their shift and can document at the point of care. Unlike current systems whereby documentation is performed later in the shift, using paper notes or relying on memory, EHR results in more accurate documentation that supports resident/patient health and safety. By using current technologies, care aides may be given a voice within LTRC and as such can feel they are a part of the greater LTRC culture change movement in being able to document their experiences and advocate for solutions they deem pertinent to remedy any issues regarding the direct care and relational aspects of their role.

Combating the Institutionalization of Care Aides in LTRC

A recent ethnographic study by Kelson (2013) found that residents in an LTRC facility were encouraged to spend much of their time outside their private rooms and instead in common areas. In these open spaces, people ate, relaxed, and generally spent most of their time under the watchful gaze of staff, and in some cases family members, volunteers, and friends. In this schema, residents of the LTRC were most visible and had reduced access to privacy, resulting in monitoring and surveillance techniques that helped keep residents safe but also created what Foucault (1977) described as a state of conscious and perpetual visibility. In this same schema, care aides can also be seen to have a loss of privacy. Care aides at Green Lodge do not have their own staff room; instead, they have a table to sit at in the supply closet. Whereas the nurses get a "nurses' station" and the residents have their own room (for privacy from other residents or staff members), there are very few places that residential care aides can escape to. Often during their breaks, care aides were seen eating in their cars or on benches outside of Green Lodge. In the interviews, they explained to me that they did this to get away from other people, to escape the gossip—in essence, to secure their privacy.

Foucault reported on how individuals who were deemed abnormal, as in the case of lepers, were cast out beyond the town walls, beyond the limits of the community and into an elusive world outside what they were familiar with (Puff, 2006). The result of this marginalization was that a physical partitioning was created, with each of the two groups being foreign to the other (Foucault, 1977). Like the lepers of Foucault's time, older adults living in institutional care are also widely considered to be secluded, isolated, and pathologized; residents are set apart in the minds of our wider communities (Kelson, 2013). Based on the results of my study, I argue that those who work directly with residents in LTRC are also set apart, perhaps not to as great of an extent as the residents they care for, but still on the outskirts of society. It has been argued that in LTRC there is the "in group" (the residents) as well as the "out group" (the staff members). I argue, however, that this is only one way to view this scenario, and that upon further reflection it is both the care aides and the residents who are the "out group" in LTRC. As Foucault (1977) stated, institutionalized individuals lack both individual privacy and visibility within greater society. One solution is that care aides be brought into the international dementia friendly (or dementia inclusive) community movement (Alzheimer's Disease International, 2015). This is discussed in depth in the following section.

8.3.3. Changing Societal Perceptions

It was evident that morale was low among care aides pertaining to their career choice. There are two main implications that have been highlighted from the findings of this study to improve morale among care aides as well as societal perceptions of the care aides' role within LTRC. The first involves incorporating the role of care aiding into the international movement for dementia friendly communities, and the second pertains to increasing the growing body of research into care aiding and the role of care aides.

Dementia Friendly Communities

Alzheimer's Disease International (ADI, 2015) defines dementia friendly communities as communities that seek to preserve the safety and well-being of those living with dementia by empowering all members of the community to celebrate the capabilities of persons with dementia and to view them as valuable and vital members of the towns, cities, villages, and countries in which they reside. Based on the findings of this study, the care aides' role gets translated into a physical task (related to excrement, to make matters worse). The relational aspect of the care aide as one of the primary or sole relationships to the individual resident, often a person living with dementia, should be brought to the attention of dementia advocates, researchers, and industry partners. There is a growing surge of dementia friendly/dementia inclusive environments occurring at this period. In the LTRC sector, care aides described themselves as the *"lowest person on the totem pole."* In the discussion of power in this thesis, it appears that care aides hold the least amount of power in LTRC. Care aides could be perceived as more powerful within their communities if they became identified as dementia carers and advocates.

Being included in the movement for dementia friendly communities may also help support care aides in alleviating the stigma associated with their role. If care aides were brought into this movement, it would help facilitate a re-branding of the role of care aides as key advocates in dementia friendly communities instead of the "ass wipers" they often seen as. Being involved in the movement for dementia friendly communities may also give care aides the power to feel that it is their duty to report any abuse they see because the community will gather around them in support. What if care aides were seen as a viable healthcare vocation and not a stepping stone or punishment for not having the resources to become a nurse? What if care aides were brought into the movement to foster dementia friendly communities, were more understood by society, and felt more empowered within the LTRC setting—perhaps less abuse toward residents would be seen.

Research Participation

Improve care aides' voice within academic literature by including them in participatory research. This will help ensure that research conducted in LTRC that pertains to care aides will ultimately positively affect care aides and their role supporting residents. In recent years, there has been an increase in the presence of participatory action research (PAR) with residents in LTRC (McKeown, Fortune, & Dupuis, 2016; Minkler et al., 2008; Shura, Siders, & Dannefer, 2011). There has also been an increase in PAR with nurses (Cusack, Cohen, Mignone, Chartier, & Lutfiyya, 2018; Mackoff, Glassman, & Budin, 2013). However, it is rarely if ever seen that PAR is conducted with the direct care staff in these settings. The findings of this study highlight the fact that care aides are not only invited to participate in research, but are also not comfortable with participating in research. It was clear in this study that taking care aides off shift to interview them was not a priority on their “task list.” As such, other forms of interviews and data collection may be a better choice in facilitating care aides’ voices to be heard.

If care aides were involved in the research process, this may allow for research that benefits the role of care aiding. PAR is a viable method to stimulate creative care aide–driven ideas and initiatives for reform within LTRC. The care aides’ experiences and expertise have been overlooked within many culture change efforts that have developed and facilitated changes from the outside and from the top down. By engaging care aides as partners in the development of future LTRC studies, they will add to the strength of the research, both during data collection and implementation of the findings. PAR with care aides would help foster the capability of this population as well as facilitate the movement of culture change.

8.3.4. Future Directions for Research

Adding to the previous section outlining the importance for PAR and care aides, another suggestion for future research is to incorporate time-sampling methodologies to assess care aides’ perceptions around the use of their time in LTRC. In spite of the labor-intensive and time-consuming nature of this type of research, time sampling has been shown to offer many advantages (Holtzman & DeLongis, 2007). By using time-sampling methods, researchers would have access to valuable and unique insights into care aides’ daily lives, their social interactions, and their current health status. Specifically, time-sampling methods allow for valuable assessments of within-person associations in daily processes (Almeida, 2005).

Future directions for research may also include the perceptions and experiences of care aides in their use of technologies for documentation. PointClickCare (2018), a Canadian company, holds the most widely used electronic health recording (EHR) platform. In their Clinician Engagement project, their technologies facilitate care staff in LTRC to do the following: (i) track and plan their shift; (ii) understand the residents' needs and preferences; (iii) document activities of daily living; (iv) manage medication observation and administration; and (v) communicate with co-workers during and across shifts. These capabilities will be delivered through a mobile phone application that connects to PointClickCare's EHR platform. Using a mobile phone allows users to connect to the EHR at any time. They will have access to all pertinent information throughout their shift and they can document at the point of care. Unlike current systems where documentation is performed later in the shift, using paper notes or relying on memory, this project results in more accurate documentation supporting resident/patient health and safety.

Although the majority of the care aides interviewed for this thesis were Caucasian, it cannot be understated that in nearly all LTRC settings most care aides are migrant female workers who are generally not Caucasian. The importance of examining ethnocultural differences among care aides, especially those who do not identify as Caucasian and who are migrant women, must be at the forefront of future LTRC research endeavors. It is truly this population who is the backbone of dementia care, and although this doctoral thesis examined the perspectives and experiences of care aides at Green Lodge, it is not a representation of migrant female workers. It is highly encouraged that continuing steps to examine the role and perceptions of care aides in LTRC should unabashedly focus on racial issues within these settings from the perspective of the care aides. As previously stated, this research should be co-conducted with care aides and employ participatory action research methods to allow care aides to become more familiar and comfortable with the research experience as well as to have the wisdom of their lived experiences guide the success of the study.

In the future, it would be beneficial to conduct this research using more than one study site, so that both anonymity and confidentiality may be ensured for participants. Another suggestion to strengthen the ethical sensitivity of this study is to have various means for participants to input data that do not include face-to-face interviews on-site at the LTRC where they are employed. A suggestion to facilitate this would be to incorporate mixed methods, such as paper survey responses and online data collection capabilities whereby participants may enter their responses privately, in the leisure of their own home (or wherever they may find access to a public computer, such as a library or Internet café), without the concerns that fellow staff members or management may see them interacting with the researcher. Access to the Internet and computers must be taken into account if this form of mixed-method data collection is to be incorporated because, as previously discussed, care aides often come from low socio-economic statuses and computer literacy and access to computers may be a more precarious situation for them then for other research participants, such as nurses or members of the management team. An ideal situation would also be for the interviewer to meet the care aides at a location of their choice, such as their home or a local café, where the care aides may speak freely about their perceptions of their role within LTRC.

Due to the significant gender divide in LTRC (with the vast majority of residents and staff members being women), it would also be important to have male interviewees available to conduct interviews with the male care aides. Perhaps with a male interviewing another male, a greater depth of gender-related differences among the care aides may be explored.

8.4. Conclusion

The following section will summarize the key findings of this thesis as well as the key recommendations. There are four key findings outlined in this thesis. First, participants reported that care aides are not adequately trained for the realities of the role. One of the key issues highlighted in this thesis was care aides' shock and concern when wanting to deliver good end-of-life care to residents because they are often not equipped to do so and were not prepared for these scenarios.

Second, participants discussed feeling frustrated because of the lack of perceived autonomy they have over their residents' care decisions as well as their inability to record. Participants expressed believing that they were the *"eyes and ears"* of the residents, yet since care aides are not allowed to report issues or even changes in care plans for their residents, they felt "voiceless," unheard, and unvalued. Inevitably, by not allowing the care aides to have a voice, both the care aides and the residents are disempowered since the care aide is the closest direct-care worker for the residents.

Third, participants expressed feeling unappreciated because there is no system put in place to reward good care aide behaviour among the care aide team. Care aides also reported feeling vulnerable due to the heavily flawed system put in place to reprimand bad care aide behaviour, which puts care aides in a precarious situation where they must work with care aides who they deem neither caring nor safe.

The fourth and final finding of this study was that care aides reported feeling unappreciated in society because they felt their role was dwindled down to the lowest common denominator of task-based care, peri-care, thus hiding the true nature of their role and value within the broader healthcare team.

Recommended solutions to these findings are as follows. First, to adequately prepare care aides for the reality of their role within LTRC, the following suggestions have been made and outlined in this chapter: (i) standardizing care aide training and education nationally; (ii) implementing screening prior to admittance in the program; and (iii) supporting care aides with education and resources pertaining to trauma and end-of-life. Second, to facilitate autonomy among care aides, it is suggested that (i) methods for documentation among care aides must be implemented; (ii) a duty to report precarious incidences must also be executed; and (iii) an emphasis on the importance of relational care must be realized within the scope of practice for the care aide role. Finally, to improve societal perceptions pertaining to the care aide role and thus improve morale among care aides, two suggestions are as follows: (i) include care aides as valued members in the movement for dementia friendly communities; and (ii) include care aides in participatory action research, further growing the body of academic knowledge pertaining to care aides and their role within LTRC.

For culture change to occur in LTRC, care aides must be positioned on the same "side of the fence" as the rest of the healthcare team (Caspar and Cooke, 2016). Care aides must be empowered and the true nature of their role be brought to light in the public eye, thereby reducing the stigma and misinformation surrounding their role in LTRC as "ass wipers" along with the stigma surrounding the residents they care for, the majority of whom have dementia. Currently care aides embody the backbone of our healthcare system for LTRC. With the coming aging population and increase in rates of dementia, this backbone must be adequately supported now in order for our society to support our aging population into the future. Until care aides are actively included in the healthcare team, understood in society, and adequately researched, their important and significant perspectives, experiences, and understanding of their residents' wants and needs will remain an untapped resource that is essential to the provision of high-quality, person-centred care in LTRC.

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Appendix A. Interview Agenda

SIMON FRASER UNIVERSITY
THINKING OF THE WORLD

1. *Tell me why you became an RCA.*

   Prompts: past experiences in LCT/ with O.A/ as an RCA

2. *Tell me about a recent shift.*

   Prompts: their position, residents, co-workers, events, complexity of care, what stood out about that particular shift? Why did you choose to talk about that shift?

3. *Describe to me a resident that you particularly enjoy caring for.*

   Prompts: care level of resident, resident's story, family interactions?

4. *It is human nature to not enjoy everyone that you care for. This example does not have to be from this facility but can you please think back and describe to me a resident that you find particularly unenjoyable to care for.*

   Prompts: care level of resident, resident's story, family interactions?

5. *Tell me about a particular co-worker that you thoroughly enjoy working with.*

   Prompts: how do they treat colleagues, residents, management, deliver care, sense of humour, communication, time management, work ethic?

6. *It is human nature to not enjoy everyone that you care for. This example does not have to be from this facility but can you please think back and describe to me a co-worker that you find particularly difficult to work with.*

   Prompts: how do they treat colleagues, residents, management, deliver care, sense of humour, communication, time management, work ethic?

7. *Tell me about a situation when you were not able to deliver the care that you wanted to deliver.*

   Prompts: organizational issues, limited recourses, staff, education, communication

Appendix B. Staff Information/Consent

Application 2014s0151

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort and safety of participants. This research has received ethics approval and is being conducted under permission of the Simon Fraser University Research Ethics Board. The Board's chief concern is for the health, safety and psychological well-being of research participants.

Permission has been granted from Green Lodge [name changed] as well as Simon Fraser University's Research Ethics Board.

SFU SIMON FRASER UNIVERSITY
THINKING OF THE WORLD

PARTICPANT INFORMATION AND CONSENT FORM

INTERVIEWS WITH STAFF:

The Impact of Staff Attitudes' towards Residents and the Delivery of Care in Long-Term Facilities

Principle Investigator:
Professor Andrew Sixsmith,
Director, Gerontology Research Centre, Simon Fraser University,
[Telephone and email provided]

Research Assistant:
Laura Booi, MA,
Doctoral Candidate, Department of Gerontology, Simon Fraser University,
[Email provided]

INTRODUCTION

You are being invited to take part in a study funded by Technology Evaluation in the Elderly.

Your participation in this evaluation is entirely voluntary, so it is up to you to decide whether or not to take part. Before you decide, it is important to understand what the study involves. This information sheet will tell you about the study, what we are asking from you, why the research is being done, what will happen during the study and the possible benefits, risk and discomfort to you.

If you wish to participate, you will be asked to sign the consent form at the end of the information sheet. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision.

Please take time to read the following information carefully before you decide.

1. Who is conducting this study?

This study is being conducted by Professor Andrew Sixsmith at Simon Fraser University in the Department of Gerontology.

2. Background

a) What is the purpose of the evaluation?

We are undertaking a study that will enable us to gain a better understanding of how care staff and residents interact in long-term residential care. To achieve this, we are speaking to residents, care staff and family members to see their perspectives. The information we receive will help us develop an understanding of how care facilities such as this can best support residents, staff and family members in the future.

b) Why have I been chosen?

You have been asked to take part in this study because you are employed as care staff in one of the facilities involved in this study. We want to talk to you about your experiences as care staff and the positive and negative aspects of working in residential care. If you decide to take part in we would like you to be involved in an interview to tell us about your experiences.

Who can participate in this evaluation?

Those who are employed as care staff at Green Lodge.

Who should not participate in this evaluation?

Those unable to speak or read English.

c) Do I have to take part?

It is up to you to decide whether or not to take part in an interview. If you do decide to take part you will be given this information sheet to keep and be asked to sign the consent form attached to this form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

d) What should I expect if I take part?

A member of the study team will contact you to agree a suitable date/time and venue for the interview. A member of the study team will facilitate the interview. An interview is a one-to-one discussion between you and a member of the research team and involves the researcher asking you a number of questions. The interview will ask you about your experience of working as care staff in residential care.

If you choose to take part in an interview this will last for between 45-60 minutes and be conducted at a date and time convenient to you.

The researcher will take regular breaks if needed and you are free to disengage from the research at any time if you do not wish to continue.

e) Will my taking part in this study be kept confidential?

If you agree your comments will be recorded and used in the study. Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. If you wish for anything to remain confidential then you can tell the researcher and they will ensure that it is not recorded.

The data from research will be stored by us for five years, and then destroyed. The data will be password protected and/or stored on a flash-drive in a locked filing cabinet.

f) What are the possible benefits of taking part?

You may not benefit directly from this study. However, we hope that what we find out from this study will help us establish how care facilities can be improved to meet the needs of care staff, residents and family members in the future. And you can help us do this.

g) What will being involved in the study cost me?

You will not incur any personal expenses as a result of participating in the research.

h) What will happen to the results of the study?

The results from this study will be reported in university papers and presented at university conferences. In all publications the results will be written in such a way that no one can identify you from the data.

4. What happens if I decide to withdraw my consent to participate?

Your participation in this study is entirely voluntary. You may withdraw at any time.

You do not waive any of your legal rights against the sponsors, investigators, or anyone else by signing this consent form.

5. What are the possible harms and side effects of participating?

There are no known harms or side effects of participating in the study.

6. Who is paying for the evaluation?

Technology Evaluation in the Elderly, is a not-for-profit organization supporting multidisciplinary research related to health care tools, technology and interventions for seriously ill elderly patients and their families.

7. Who is carrying out the evaluation?

The evaluation is being carried out by Andrew Sixsmith and Laura Booi in the Department of Gerontology, Simon Fraser University.

8. Who do I contact if I have questions about the evaluation during my participation?

If you have any questions or desire further information about this evaluation before or during participation, you can contact **Laura Booi at [telephone provided]**

9. Who do I contact if I have any concerns or complaints about how this evaluation is being conducted?

If you have any concerns or complaints with respect to your participation in this research evaluation as a research participant, please direct them to Dr. Jeffrey Toward, Director, Office of Research Ethics at [email and telephone provided]

PARTICIPANT CONSENT TO PARTICIPATE

I have read and understood the subject information and consent form. ☐

I have had sufficient time to consider the information provided and to ask for advice if necessary. ☐

I have had the opportunity to ask questions and have had satisfactory responses to my questions. ☐

I understand that all of the information collected will be kept confidential and that the results will only be used for the evaluation objectives. ☐

I understand that the interview or focus group will be audio recorded. ☐

I understand that my participation in this evaluation is voluntary and that I am completely free
to refuse to participate or to withdraw from this evaluation at any time without changing
in any way the quality of care that I receive. ☐

I understand that I am not waiving any of my legal rights as a result of signing this consent form. ☐

I understand that there is no guarantee that this evaluation will provide any direct benefits to me. ☐

I have read this form and I freely consent to participate in this evaluation. ☐

I have been told that I will receive a dated and signed copy of this form. ☐

Your signature indicates that you consent to participate in this evaluation.

Signatures

Printed Name of Participant Signature Date (yyyy/mm/dd)

Printed Name of Principle Investigator/ Signature Date
(yyyy/mm/dd)
Designated representative

Principle Investigator:
Professor Andrew Sixsmith
Director, Gerontology Research Centre, Simon Fraser University,
[Telephone and email provided]