Addressing the Strengths and Gaps in Education and Training for Long Term Care Staff Who Provide Direct Care to Individuals Living With Dementia

By

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Abstract

The number of residents living with dementia in long term care continues to grow as the prevalence of dementia in the population increases. Caring for individuals with dementia presents additional challenges for family members who may remain involved in their care and for long term care nursing staff who provide their direct care. Providing quality dementia care requires adequate staff education and training. The purpose of this study is to address the need to better educate and train staff who provide direct care to residents living with dementia in long term care. This was done by conducting a qualitative study within one long term care facility in the Winnipeg, Manitoba area. The researcher explored what training currently exists for long term care staff members in this facility who provide direct care to individuals living with dementia, what issues or gaps were perceived by staff and family members in the current provision of dementia education and training, and how the provision of education and training can be improved to provide maximum benefit to the staff, residents, and family members. For the purpose of this thesis, “long term care” refers to the care that older adults living with dementia receive who reside in nursing facilities and who can no longer be cared for in their homes or within the community. The results of this research indicated that there are areas where education and training is thriving but many areas in need of further development.

Keywords: Dementia, Long Term Care, Education and Training, Seniors, Staff

Acknowledgements & Dedication

This thesis is written for all of the older adults living with dementia in long term care, their family members, the staff members who provide their care, and the facilities that house them. It is written in the hopes that these findings can help to increase the quality of care and life for these individuals by drawing attention to the need to continue making advancements towards educating individuals about dementia and by giving their caregivers the proper tools to provide the best person centered care possible.

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CHAPTER ONE: INTRODUCTION & LITERATURE REVIEW

Statement of the Problem

Emerging behavioural symptoms and progressive functional decline may result in the placement of older adults living with dementia into a long term care facility (Barton, Miller, & Yaffe, 2006). These occurrences increase the need for formalized care and therefore, the need to have efficiently/properly trained staff members who will be comfortable and well trained in providing care to residents with dementia. Providing care to someone with dementia requires specialized knowledge and approaches as behavioural and psychological symptoms of dementia displayed by some residents can be particularly challenging for long term care facilities. It is especially challenging for long term care facilities characterized by a lower skilled workforce (Barbosa, Nolan, Sousa, & Figueiredo, 2014) to be adequately prepared for the challenge if they are not properly educated on dementia care approaches and issues. For this reason, there need to be improvements in basic and continuing dementia care education for direct care staff (Morgan, Stewart, D'Arcy, & Forbes, 2005).

A large number of nursing home residents have some form of dementia. In the literature, estimates of the prevalence of residents with some form of dementia range anywhere from 50-80% (Barton, Miller, & Yaffe, 2006; Seitz et al., 2012; Williams, Hyer, Kelly, Leger-Krall, & Tappen, 2005). The purpose of this study is to provide an introductory look into the current dementia education and training for staff in long term care who work with individuals living with dementia in long term care. Some studies have looked at the benefits of dementia education and training. For example, Bowers (2014) examined the benefits of dementia training which included improvement in the delivery of care to residents, improved staff satisfaction, and job retention.

This study explores the benefits as well, but is unique because it also asks staff and family members what can be improved within their current opportunities for education and training to in order to produce more positive outcomes for everyone involved. Specifically, it draws attention to the need for continual development in education while also highlighting the benefits of doing so. By utilizing a qualitative approach, it explores both strengths and gaps that staff and family members perceive to be present This was done by conducting a study using thematic content analysis of one long term care facility as the means for a qualitative approach. The study examined the thoughts and beliefs of staff members who provide direct care to individuals with dementia as well as family members of individuals living with dementia in long term care.

Long term care is provided in many ways and may include community services, continuing care retirement communities, hospitals, supportive housing programs, and nursing homes. For the purpose of this thesis, long term care shall refer to the care that older adults living with dementia receive, who reside in nursing facilities and who can no longer be cared for in their homes or within the community. In comparing the care for nursing home residents without dementia, caring for the residents with dementia requires more manpower (Lee, Hui, Kng, & Auyeung, 2013). It becomes important then, to address how the current provision of care to these individuals can be improved through the examination of how it is currently being provided. An essential element in the care of people with dementia includes appropriate staff training (Alzheimer's Association, 1997) to meet the special needs of this population. This study provided a unique look into the current provision of dementia care in long term care through the eyes of those who are affected directly by it: family and staff. This study may help researchers and health care professionals to better understand what is currently being offered and what can be done in the future to improve the provision of education and training for direct care staff within these health care settings. It is important to identify the potential gaps in the current provision of education and training in order to be able to make advances in improving the current provision.

Key Questions Include:

1. What training currently exists for long term care staff members in Manitoba who provide direct care to individuals living there with dementia?
2. What strengths as well as issues or gaps are perceived by staff and family members in the current provision of dementia education and training for staff members in long term care?
3. How can the provision of education and training for staff and families be improved to provide maximum benefit to the staff, residents, and family members?

A Background on Dementia/Prevalence and the Importance of Dementia Education and Training's Impact on Various Groups

The population is aging. According to the World Health Organization (2013), the proportion of the world's population aged more than 60 years is expected to double from approximately 11% to 22% between 2000 and 2050 or more specifically, from 605 million to 2 billion people. People are also living longer which amplifies the chance that more people will be developing different forms of dementia in the population. Should this be the case, it will also increase the number of older adults requiring formal care.

Furthermore, dementia is on the rise and the global impact of dementia is expected to increase (Kelly, 2010). Dementia is an umbrella term, often used to describe a group of disorders that affect a person's memory and cause irreversible cognitive decline (Alzheimer's Association, 2007). This decline is often a result of various biological mechanisms damaging brain cells (ibid). Dementia is caused by damage to nerve cells in the brain and as a result of the damage, neurons are no longer able to function normally and may die (ibid). When a person develops dementia it leads to changes in their memory, behaviour, physical abilities, and their ability to think distinctly. The most common form of dementia is Alzheimer's disease and it accounts for approximately 63 per cent of dementia cases (Alzheimer Society, 2010). According to the Alzheimer Society (2010), approximately 500,000 Canadians have dementia today and it is the most significant cause of disability among Canadians over the age of 65. Dementia costs Canadian society many billions of dollars each year and forecasts predict that there will be, "65.7 million [people] in 2030 and 115.4 million [people] in 2050" (World Alzheimer Report, 2009) that have some form of dementia. Furthermore, forecasts predict that within 20 years the worldwide prevalence of dementia will increase two-fold (ibid).

There is a common misconception that Alzheimer's disease is the only form of dementia but in reality, there are a wide variety of dementias that may affect a resident living in long term care. The following summaries were retrieved directly from the Alzheimer Society Website (2015). They highlight differences amongst some of the more common dementias in the population:

- Alzheimer's: The most common cause of dementia. During the course of the disease, the chemistry and structure of the brain changes, leading to the death of brain cells.
- Lewy Bodies: This form of dementia gets it's name from tiny spherical structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue.

- Vascular Dementia: If the oxygen supply to the brain fails, brain cells may die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes.
- Fronto-Temporal Dementia: In fronto-temporal dementia, damage is usually focused in the front part of the brain. Personality and behaviour are initially more affected than memory
- Creutzfeldt-Jakob Disease: Prions are infectious agents that attack the central nervous system and then invade the brain, causing dementia. The best-known prion disease is Creutzfeldt-Jakob disease, or CJD.
- Korsakoff's Syndrome: Is a brain disorder that is usually associated with heavy drinking over a long period. Although it is not strictly speaking a dementia, people with the condition experience loss of short term memory.

Dementia affects a person's ability to perform everyday activities and there are increasing numbers of people with dementia being admitted into long term care facilities (Barbosa et al., 2014) as a result. The variety of dementias present in the population increases the need for informed training for care staff that highlights the differences between them. Doing so will minimize the areas in which long term care provision is currently lacking.

Literature Review

According to the literature, there are a variety of areas in long term care dementia education and training that can be improved. Many long term care facilities lack in-service training sessions for nursing staff and training that is offered is often uncoordinated and inconsistent (Nishita, Hayashida, & Kim, 2014; Stone & Barbarotta, 2010) from region to region (Kelly, 2010). Standardized training requirements are important for enhancing the quality of care that residents receive (Nishita et al., 2014). There are also many gaps in delivering person centered care, despite its recent encouragement into care provision as well as overall service gaps and a lack in effective communication training between staff and residents (Parbury, Chenoweth, Jeon, Brodaty, & Haas, 2012). This is unfortunate because poor person centered care has been linked to lower resident quality of life in long term care facilities (Terada et al., 2013) and ineffective communication has negative effects on care provision. Furthermore, a notion exists that people living with dementia lose all ability to communicate effectively as a result of the disease which contributes further to communication issues between staff and residents.

A gold standard does exist for providing dementia care. Currently, “providing a good quality of life (QOL) has been recognized as the main goal of currently available dementia care” (Terada et al., 2013, p. 103) but consistent and ongoing regulation has not been available for assessing dementia care (ibid). This is problematic when it comes to assessing criteria validation and makes measuring effectiveness of the gold standard problematic. The non stimulating and cursory nature of many continuing education programs paired with an overwhelming amount of new information involved in training has been viewed problematic. Staff may be less likely to participate in continuing education because of this (Ghandehari et al., 2013). Other issues include staff feeling rushed, a lack of access, and the stressfulness of long term care, to name a few. Of particular relevance was a study conducted by Estabrooks, Squires, Carleton, Cummings, and Norton (2015) who explored the issue of unregulated workers in long term care who provided care to individuals living with dementia. They highlighted the issue of care-provider burnout as well as the need to develop better training standards and education in long term care. To clarify, in the article, unregulated workers within long term care facilities refer to the personal support workers who are responsible for the every day care of residents. These workers assist residents to preform activities of daily living which in crude but are not limited to bathing, toileting, and eating. These issues are touched on in subsequent sections.

Improvements for Education and Training are Needed

Research has shown that training is important for job satisfaction and job retention among staff in long term care (Sung, Chang, & Tsai, 2005) and opportunities for more training have been found to be important for job satisfaction (Maas, Buckwalter, & Specht, 1996; Atchison, 1998; Karner, Montgomery, Dobbs, & Wittmaier, 1998). Enriching the work environment is important. Staff who are more comfortable in the work place are less likely to be stressed and thus, more likely to provide better care to the residents. Staff are entitled to have a work environment that is both supportive and enriching (Sung et al., 2005) and should receive training as soon as they are hired that is supervised by management and offered in a continued fashion (Bowers, 2014).

The requirements of staff training in dementia care are not synonymous from facility to facility and there is a lot of variation in how it is provided depending on different geographical areas (Bowers, 2014). Different facilities require different levels of training; however, there needs to be a baseline model for dementia care training because variation in training is setting up the potential for confusion and poorer care quality. There need to be standards in place to assure that residents in every long term care facility are receiving appropriate care to meet their individualized needs. Family members also need to be provided with opportunities for education and training on dementia, as training family is beneficial and assists them with learning to appreciate approaches taken by staff members. It also allows them to remain actively involved in the care of their family member(s) and helps them to understand the progression of the disease better and complications associated with it (Bowers, 2014). Subsequently, sufficient time for training material coverage is paramount to the success of any training measures (Nakhnikian, Wilner, Joslin, & Hurd, 2002). If staff and families are rushed in learning, there is a greater chance that information will not be retained. Training will only be beneficial if implemented in an appropriate and well thought out fashion.

Training needs to cover the basics of dementia, effective communication strategies, understanding behaviours, food and hydration issues, pain assessment and understanding resident pain, the importance of remaining socially connected in having dementia, understanding wandering, falls prevention, how to minimize restraints, and end of life care (Bowers, 2014). As well, there needs to be more attention paid to the recognition, prevention, and management of distressful behaviours (Williams, Hyer, Kelly, Leger-Krall, & Tappen, 2005). These include but are not limited to: agitation, pacing, exit-seeking, combativeness, withdrawal, and repetitive vocalizations (ibid). Varying dementias require varying approaches and so training must be developed to encompass a wide range of specialized issues. It should also be highly focused on personhood and learning how to incorporate less clinical-based interventions to care. A shift from task orientation to person centered care is essential. Managers may find it beneficial to inform their nursing staff of resident biographies upon entry into the facility. This would encourage more person centered care. It would also be useful to certify that staff are given adequate time and opportunities to maximize the residents' abilities during basics personal care (Barbosa et al., 2014). Person centered care has the potential to improve the quality of dementia care and job satisfaction (Lee et al., 2013). If the staff providing care are happy, then the residents receiving the care, as well as their families are more likely be happy as well.

Needless to say, there have been strides made in the current care provision for individuals living with dementia in long term care. There are still many areas with room for improvement in order to benefit the staff, families, and most importantly, the residents living with dementia further. Strategies on how to better educate and train long term care staff working with this vulnerable population is extremely important for continual improvement in care provision and quality of care and life. To highlight the need for better education and training, the subsequent sections will focus on a discussion of ageism, it's framework, and why it is important to consider. This is followed by sections on how dementia education training impacts staff, family, and residents in various ways. The goal is to provide an overview of why such training is relevant.

Having worked in a long term care facility as a Health Care Aide, I have become aware that working directly with someone who has dementia can be challenging. They may be more difficult to communicate with and sometimes become aggressive (Bowers, 2014). Irvine, Beaty, Seeley, and Bourgeois (2012) note that inadequate training of those who provide direct care has been linked to substandard care. This may result in a profound impact not only on the person living with dementia and on the care staff, but potentially also for the families whose family member is living with dementia. This has been my experience working in this setting as well.

There is a growing demand for higher quality care in long term care facilities as the number of individuals living with dementia increases (Barbosa et al., 2014). This is paired with the need to address current training interventions to deal with the shortage of competent direct care workers (Barbosa et al., 2014). Dementia gives rise to many issues that are quite challenging. These include but are not limited to both communication and safety. Staff must understand how to deal with these challenges accordingly (Bowers, 2014). Sufficient training impacts not only the staff and residents themselves, but also the resident's family members and the health of the individual with dementia. Staff who are properly educated and trained in dementia care will be more confident in providing care. They may also find more satisfaction in their work, will be less likely to leave their positions, and deliver improved care where this education and training is sufficient (Bowers, 2014). When staff are well trained, families will likely be more satisfied with the quality of care that their family members are receiving. The resident's quality of life will also be improved. Quality of life is a broadly defined term within literature and often refers to a certain standard of health or comfort that an individual experiences. In this case, quality of life refers to the happiness and comfort residents experience as a result from social engagement and personalized care. A resident with a high quality of life will be one that has their basic physical and mental health needs attended to while also experiencing social and personal engagement. The combination of these things will presumably increase the overall comfort of the resident and therefore, promote health and happiness. Individuals living with dementia are considered to be a vulnerable population and thus, there is a moral imperative to consider their unique care needs. In doing so, all individuals affected by this issue (staff, family, and residents) will see positive improvements. The following section explores the issue of ageism as it relates to dementia care. Following this, sections will highlight how different groups of individuals are affected by adequate or insufficient dementia education and training offered in long term care.

The Ageism Framework and Ramifications on Dementia Care

Age discrimination towards older adults is not a new concept but rather, an issue that continues to evolve within the framework of current society. Robert Neil Butler (1969) coined the term ageism, arguing that it functions as another form of bigotry and essentially represents a, “deep seated uneasiness on the part of the young and middle-aged—a personal revulsion to and distaste for growing old, disease, disability; and fear of powerlessness, "uselessness," and death” (p. 243). Ageism is not considered a theory however, the framework of ageism and the existence of ageism towards older adults within the population is important to consider when thinking about what applications age prejudice or discrimination has in the field of aging. Specifically, it is important to consider how ageism and ageist views affect the quality of care individuals with dementia receive. In a broader sense, it is also important to understand if and how these negative views further perpetuate people’s individual fears of growing old. All human beings have the potential to be ageist and which is concerning considering the advancement in the aging of the population. In order for individuals in upcoming generations to experience positive aging experiences, there needs to be a reduction in age discrimination.

Why Does Ageism Exist?

Ageism has become embedded in the framework of society to the point where it has become ingrained in the various social structures, policies, and institutions that encompass today’s culture. To a certain degree, this embedded ageism is making it increasingly difficult to avoid having ageist attitudes in the population because ageism has become subconsciously normalized in people’s day to day lives. Several theories have been used in an attempt to explain the existence of ageism. Within the literature, three surface frequently: Social Identity Theory, Terror Management Theory, and Social Role Theory. Bodner (2009) argues that in Social Identity Theory, individuals form in-groups on the basis of shared characteristics and then show biases that favour their in-group compared to the out-group. Jonson (2012) adds, “non-old people may uphold ideas about older people as “the other” by constructing their own future selves as essentially different from that of older people of the present” (p. 198). In this case, younger adults view themselves as the in group while categorizing older adults as the out group. Perhaps people hold innate fears of aging because they do not understand the normal aging process and use this fear as a rationale to separate themselves from the current older population. Similarly, Blaine (2013) suggests that older adults prompt a wide range of emotions and negative feelings among youth. Terror Management Theory explores ageism as a response to humans mortality awareness by suggesting that in an attempt to deny death, individuals will distance themselves from older people and from thoughts of becoming old and disabled in any way (Greenberg, Pyszczynski, & Solomon, 1986). In this theory, death and decline are viewed as being inevitable and so individuals will often disassociate themselves from reminders of decline and disability (i.e. older adults who have dementia). Consideration of this theory may provide some understanding of ageism however, it is unlikely that every individual will fear death and decline to the extent that it causes ageist behaviours, making it a less than ideal model to follow in an attempt to understand ageism. Finally, Social Role Theory argues that, “when we observe others, we pay attention to the social roles they occupy” (Kite, Stockdale, Whitley, & Johnson, 2005, p. 243). It is accompanied by the notion that if an individual can no longer contribute to greater society, they are not useful or worthy of the same level of respect as the other members of society.

All three of these theories provide suggestions as to why and how ageism functions in some situations but no one theory seems to be able to explain exclusively why ageism exists. Perhaps this is because ageism is such a complex concept and cannot be defined by one explanation. Regardless, it is still useful to examine to what degree and why ageism is present in care provision in long term care facilities for older adults with dementia. Among the three aforementioned theories, Social Role Theory seems to be most applicable to care provision. In long term care, individuals who have dementia may be seen as having little worth since they are unable to occupy roles that society deems as being important. Social Role Theory emphasizes the concept of usefulness. Individuals who have dementia and are cognitively limited may become written off or dismissed if staff or family members do not perceive them to be useful anymore. These residents may not be taken as seriously when expressing their concerns, pain, or wishes in long term care because of the stigma that is often associated with a person who has dementia. They become marginalized and are often taken far less seriously than a healthier person would be. In some cases, staff in long term care facilities, “other” older adults with dementia. That is, they categorize individuals who have dementia based on their disease and forget to acknowledge the individual person for who they are (Doyle & Rubinstein, 2013).

According to Doyle & Rubinstein (2013), “othering is a process that is undertaken by individuals to identify those people who are classified as different in a negative way or categorically both distinct from and of lesser significance than one-self and accepted social norms” (p. 953). The person with dementia is no longer considered a person when othering occurs. They become lost in the categorization of having a disease. Subconsciously and sometimes consciously staff members will disregard older adults with dementia and essentially place them in a non-human position. Doyle & Rubinstein (2013) also describe having dementia as having a master status. Dementia serves to label individuals socially within long term care homes negatively to the point where every action or reaction they have is no longer a result of their personal wants or needs but because of their dementia. Sometimes staff are too quick to attribute various behaviours to the disease rather than consider the possibility that there are other explanations for certain behaviours. For example, a person who wanders may have walked all of their lives and so this behaviour should not really be considered out of the norm.

Non person centered care and the process of othering de-humanizes the older adult. It is almost as if developing dementia takes away one's personhood. When othering occurs towards individuals with dementia, that individual becomes viewed as a lesser person unworthy of staff's respect or active listening. If a resident is being othered, staff will not view the resident's speech as expressions of real concerns or desires. Staff will be too focused on attributing all behaviours and issues to the person's dementia rather than looking at the person themselves. Moreover, staff will sometimes ignore direct needs of residents, dismissing them as behaviours and not real wants, desires, needs, or concerns. Dementia has profound effects on individuals who have it. There is no questioning the fact that memory often declines some and individuals may, "lose pieces of themselves" as their dementias progress. This does not mean that the entire person becomes lost. They may have this disease but this disease should not and does not define them. Doyle & Rubinstein (2013) address this lack of engagement well within their article. Staff often talk over residents or do not include them in conversations because they do not believe there is any benefit in doing so. Whether these actions are intentional or not, they contribute to dehumanizing residents (Kitwood, 1997). Residents would benefit from staff making an effort to avoid doing this.

Ageism is particularly important to consider when trying to understand how it effects the care provided to residents living with dementia in long term care facilities. There is a risk for residents to be looked after by people who may uphold ageist beliefs or attitudes. This is concerning because the ultimate result will be substandard, low quality care and poorer quality of life for residents (Irvine et al., 2012). This risk is heightened in cases where intentional or non intentional othering occurs. It is extremely important for staff in long term care settings to receive proper and recurring education and training aimed at appropriately dealing with older adults with dementia.

The concept of ageism is quite diverse. No one theory seems to be able to explain the exact reason(s) individuals have ageist attitudes and assumptions. Be that as it may, there are still things that can be improved on in order to begin addressing the issue. First, there is room to further develop the definition of ageism by including a piece about the normal aging process and how misinformation about aging causes ageist attitudes. Further development of the current theories on ageism will also be useful since no one theory seems to be able to explain ageism on it's own. Furthermore, a broader definition of health is needed; one that does not focus solely on physical health in age since health itself is diverse and means different things to different people. Lastly, proper training for those who work with older adults is necessary in order to reduce what may or may not be subconsciously ageist behaviours towards them in long term care. Addressing and working towards combatting ageism will be beneficial to the residents who receive care in long term care, the staff who provide that care, and the family members of individuals who have dementia and live in these facilities. Each of these groups are affected by ageism in the provision of care and thus, it is paramount to consider ageism when considering bettering care quality.

Care and Quality of Life

Nursing staff are central to resident quality of life (Zimmerman et al., 2005) and providing a good quality of life is the main goal of dementia care (Terada et al., 2013). If there are certain issues with care provision, they will have a direct negative effect on the quality of care that residents in long term care receive. In other sections of this document, it is made apparent that there are several areas in which training has the potential to impact the quality of care and life for residents living with dementia. In particular, the stressors experienced by nursing staff are important to consider for their own well being as well as the well being of the family members and residents they take care of (Zimmerman et al., 2005). In areas where staff are struggling, the residents will be affected. If staff are stressed, unhappy, and inadequately trained, residents will be the brunt of these issues. The quality of care for people with dementia suffers from extremely high turnover rates and shortages of direct care staff (Coogle, Head, & Parham, 2006). Furthermore, staff/caregiver well being impacts the well being of residents with dementia and therefore, the overall care quality of residents (Bramble, Moyle, & Shum, 2011; Gaugler, 2005; Gaugler & Ewen, 2005; Zimmerman et al., 2005). This is why keeping staff happy and properly educated is important. Being unsatisfied in the workplace will result in poorer care outcomes and at the end of the day, it is about making the resident's lives better. Workers are more satisfied when they perceive themselves to be well trained in dementia care (Zimmerman et al., 2005) and are more likely to adopt a person centered care approach when they are trained sufficiently. More attention must be paid to training staff in dementia care as it will increase the quality of life of the residents (Parbury et al., 2012) and promote better well being among staff members and family.

Individual Residents and Person Centered Care

Of all the aforementioned individuals affected by the proper implementation of dementia education and training in long term care for staff, it is the residents living with the disease who are arguably the most vulnerable. After all, these residents are being placed in the facilities and are in need of other people's assistance. They are no longer able to care for themselves and thus, they fall at the mercy of the staff working within long term care to assist them. Over the 1980s and 1990s, better approaches to caring for individuals with dementia began to grow as increasing attention was being paid to disability rights. The low level of institutionalized care, paired with these developments were responsible for leading the movement to better dementia care (Passalacqua & Harwood, 2012).

The person centered care framework developed by Kitwood (1997) was thought to be, and currently still is looked at for being the ideal approach for dementia care. Kitwood argued that people with dementia who receive care within a long term care facility are at risk of depersonalization because they are consistently undermined. Depersonalization may be a result of a dialectical interplay between neurological alterations in brain function and exposures to negative social environments. As a result, there is an unintended iterative negative spiral that often leads to psychological damage to residents living with dementia in long term care (Kelly, 2010). The person centered care approach focuses in on the individual resident's personality or personhood. It forces staff to pay attention to individual behaviours as a response resulting from a set of unmet wants or needs. Staff members who utilize a person centered care approach do not scapegoat the resident’s disease as the only reason for selected behaviours. Dementia is not used as an excuse to ignore individual needs but rather, prompts staff to understand what can be done to manage behaviours in a way that fulfills the resident’s individual desires. When a person centered care approach is not used, residents often have unmet wants and needs (Wang, Hsieh, & Wang, 2013) which results in poorer quality of care and life. The physical environment should be designed to support cognitive and functional abilities, promote safety and encourage independence of residents (Alzheimer's Association, 1997; Ragneskog, Gerdner, & Hellström, 2001). Depending on the capacity for understanding of residents, it may become difficult for them to know what is being asked of them. Adapting approaches to meet individual resident needs is important in order to ensure they do not become overwhelmed (this may sometimes result in resident agitation and other behaviours). Improperly trained staff place residents at a high risk for abuse. Behaviours may be misinterpreted and in some cases, taken personally, resulting in the potential for staff to become abusive (in extreme or prolonged cases of dealing with a challenging resident). This is why there is a continuing need to develop person centered care approaches within long term care facilities. In doing so, one may anticipate a reduction in certain behaviours among residents and an increased satisfaction among staff members.

Interactions with residents living with dementia are different than that of other residents. In fact, it has been noted within the literature that interactions in different contexts with different residents may require a different approach by healthcare professionals (Hughes, Bamford, & May, 2008). In a long term care facility environment this becomes especially important to consider. Resident needs must be met. By adopting various approaches to care, staff may ensure that the individual needs of each resident are being taken care of in more appropriate and efficient ways (Brown Wilson, 2009; Brown Wilson, Swarbrick, Pilling, & Keady, 2013). The aetiology of a person's dementia is important to consider. Diagnosing residents with the correct cognitive impairment has implications for how staff can deliver higher quality of care (Algase et al., 2006). Behaviours displayed by residents are not simply a function of an illness but instead, are expressions of personal needs, wants, or desires. Some of these needs may include but are not limited to: the human need for affection, attention, or sensory stimulation (Parbury et al., 2012). Every behaviour has meaning and residents who display behaviours often do so according to the attention and care they receive surrounding their individual wants and needs. More meaningful interactions will increase resident well being (Kelly, 2010) and the improvement of dementia care standards has the potential to affect the quality of life of residents living with dementia (Terada et al., 2013). At this point, it may be useful to note that not all residents who develop dementia are cognitively intact to begin with and that this thesis is not aiming to present the underlying assumption that this is the case. In fact, there is often diversity among residents with dementia and it is important to be mindful of those who might develop dementia on top of cognitive impairments they might have been born with. More and more people are aging with intellectual disabilities (for example, with Down syndrome) and some of these people are more susceptible to dementia. Other people with dementia have not been born in Canada and have not been aging here for very long. All of these individuals are unique and should also be considered because their aging their needs are different from one another. Again, there is no underlying assumption that all people with dementia were cognitively intact to begin. Dementia is quite diverse and may affect many groups of individuals. Training staff how to properly manage these residents and residents who were born cognitively intact to begin with will decrease the chances of abuse among residents living with dementia since they will be more equipped to handle their behaviours. As a result, resident needs will be more likely to be met and therefore, increase the quality of life of the individuals.

Institutions/Other Residents

Long term care facilities that do not adequately train staff are more likely to receive a bad reputation that may affect the willingness of families to want to place their family members in certain facilities. Unfortunately, providing adequate numbers of knowledgeable and skilled workers who are able to provide care to older adults and persons with disabilities is in poor supply (Nishita et al., 2014). In fact, directors of special care and non-special care units in long term care facilities noted that adequate staff training was one of their greatest challenges (Morgan, Stewart, D’Arcy, & Werezak, 2004; Morgan et al., 2005). Furthermore, staff are often responsible for monitoring interactions between several individuals and residents living with dementia may sometimes live amongst more cognitively intact individuals. This poses a problem when impaired residents display behaviours that are uncontrolled. For example, a resident who wanders in and out of rooms may cause disruption to others. As well, someone who displays particular eating behaviours or repetitive behaviours may aggravate or agitate other residents who do not understand why they are acting in particular ways. In cases where these interactions prove to be harmful to one or more other individuals, appropriate care interventions need to be utilized (Barton et al., 2006; Ragneskog et al., 2001). These interventions will produce better outcomes for residents and staff. Other residents may also be placed at an increased risk of harm where residents living with dementia display more difficult and escalatory behaviours. Training staff to understand different behaviours and how to best approach and communicate with residents to avoid agitation, aggressiveness, and other behaviours is important not only for their safety and well being, but for the safety and well being of other residents as well. Implications of adequate staff education and training on dementia extend far beyond the scope that one might suspect. It is an issue that affects the entire facility and needs to be taken into consideration more frequently as strategies are developed to improve the current care provision.

Staff

The condition of caregivers and quality of life are related to one another (Terada et al., 2013). Direct care staff feel that their work is unappreciated (Barbosa et al., 2014) and turnover rates within long term care is a growing issue in the health care community (Levi-Storms, 2008). This is concerning considering the pivotal role that direct care workers play in the quality of care and the quality of life of older adults living with dementia in long term care (ibid). Direct care workers in long term care facilities need to receive adequate preparation for their caregiving roles. Specifically, they should be receiving dementia specific training to adequately prepare them to work with this population (Alzheimer's Association, 2004). Dementia specific caregiver training has the ability to affect turnover, improve job satisfaction, and reduce staff burnout (Morgan et al., 2005). Training targeted at managing problem behaviours has the potential to increase job satisfaction and reduce staff burn out. Direct care staff who are specifically trained to care for residents living with dementia will be better prepared to deal with stress resulting from their jobs. Burnout in long term care facilities is high and the added stress of dealing with more challenging residents will intensify the chances of staff experiencing stress and the chances of becoming burnt out. If staff are more satisfied, it is safe to assume that the level of care for residents will be better and thus, the quality of the residents' lives will be improved. Residents living with dementia bring additional challenges to the caregiving situation and so learning how to deal with these stressors becomes paramount for staff and resident well being.

By understanding the individual types of dementia, staff will be better able to enforce or be prompted to use different interventions in different situations (Barton et al., 2006). Furthermore, the interventions chosen in these situations will be suited to the situation and the person living with the disease more accordingly. Staff often report feelings of emotional and physical exhaustion that emerge as a result of residents' behaviours within these settings and providing direct care to those living with Alzheimer's and other dementias are at a particularly high risk for burnout (Mackenzie & Peragine, 2003; Passalacqua & Harwood, 2012; Takai et al., 2009). These findings are significant since they were produced from those directly involved in the day to day care of residents and give light to certain insights that may be useful in assisting the design of more effective training interventions (Barbosa et al., 2014). Furthermore, it has been shown that job stress of staff, burnout, and turnover are associated with physically aggressive behaviour in those with dementia (Morgan et al., 2005), amplifying the need to further develop education and training. Identifying and ignoring the correct cognitive impairment of each resident has major implications for how staff can approach and deliver a higher quality of care that improves resident quality of life (Barton et al., 2006) and that decreases staff burnout and stressors. By addressing the difficulties of staff members, it will be easier to develop more effective training interventions that are informed; an essential requirement as the demand for higher quality dementia care increases (Barbosa et al., 2014). Moreover, when any new knowledge is provided to staff, reinforcing strategies must be developed to ensure that learning is transferred into practice. It is one thing to provide education and training, and another to facilitate enforcement of what training is provided.

Working in LTC is Stressful

The majority of workers in long term care are paraprofessional care providers hired to meet the basic needs of residents. These include feeding, bathing, toileting, and providing emotional support to those living within the facility. All of these tasks are important for resident well being and quality of life but contribute to the stressful nature of long term care facilities. The long term care facility environment can be stressful for a variety of reasons. They are often characterized by high turnover rates (Helmer, Olson, & Heim, 1993; McDonald, 1994; Maas et al., 1996; Sung et al., 2005), poor working conditions (Monahan & McCarthy 1992), low wages (Helmer et al., 1993; Sung et al., 2005), understaffing (Monahan & McCarthy, 1992), encompassed by a heavy workload (Sung et al., 2005), and are not always equipped with adequately trained workers (Helmer et al., 1993; Lee et al., 2013; Maas et al., 1996; Sung et al., 2005). All of these issues combined also contribute to a high level of burnout among staff in long term care; an issue mentioned in the aforementioned sections. With staggering numbers of older adults anticipated to enter long term care in upcoming years, these problems are concerning and need to be addressed.

Turnover is affected by all of the issues highlighted above and in some cases, the combination of those issues becomes burdensome and causes burnout among staff. Understaffing puts workers at risk for injury, burnout, and stress. It also places the residents at various risks including mistreatment, poorer quality care, and in some extreme cases, abuse. Since there is a growing need for workers in this area to support the rising number of older adults requiring formalized care (Zimmerman, Sloane, & Heck et al., 2005; Zimmerman, Sloane, & Williams et al., 2005; Zimmerman, Williams, & Reed et al., 2005), it is important to consider what improvements can be made to reduce turnover among staff (Passalacqua & Harwood, 2012). High turnover rates interrupt the quality and continuity of care that residents receive (Helmer et al., 1993; McDonald, 1994; Maas et al., 1996; Sung et al., 2005). By addressing barriers to care as well as how to make staff members' lives better, improvements can be made within facilities that will hopefully contribute to a reduction in staff turnover. Staff are also faced with heavy workloads in long term care that add to the stressful nature of the facility. There are often many residents to care for and few staff members to do so. In units occupied primarily of individuals living with dementia, this care load increases since the disease prompts the need for specialized care interventions. Staff become over worked, over stressed, and unsatisfied. It is important to note too, that some of this dissatisfaction among staff members has been linked to them feeling inadequately trained and educated on dementia and approaches in care (Helmer et al., 1993; Lee et al., 2013; Ragneskog et al., 2001; Sung et al., 2005).

In some cases, staff have expressed that they aren't as confident as they could be in dealing with a resident living with dementia. Specifically, there is concern and discomfort in dealing with residents who express aggressive behaviours but there is also an overall discomfort among some (Ragneskog et al., 2001). In some cases, staff feel as though specific units are not designed to properly accommodate those living with dementia (ibid). Many direct care staff are not well trained in dementia care (Maas et al., 1996). This adds to the stressful nature of long term care facilities and so, properly designed units and adequate education and training are needed. These will aid in providing a better suited space for residents and will improve the quality of care provided and received within these facilities. The literature also noted that many staff feel helpless and hopeless when providing direct and more personalized care to residents with dementia (Roper, Shapira, & Beck, 2001; Sung et al., 2005). Dealing with these residents is stressful and will often require more specialized training for staff in order to allow them to feel more conformable in providing care. It should be noted however, that despite there being more awareness of the need for dementia education and training, Lee et al. (2013) found that experienced staff were not any more willing to receive further training despite knowing this. This suggests that work experience ceases to be associated with either willingness to receive further training or commitment to stay in dementia care (Lee et al., 2013). Even so, there is evidence that proper education and training for staff is beneficial to improving the stressful nature of long term care.

Staff Don't Have Time

Care workers are often unable to preform the type of care they wish to because of time constraints, staff shortages, and pressures (Barbosa et al., 2014). A major barrier to proper dementia care is the fact that staff in long term care facilities often lack the time to provide personalized one on one interactions with residents that exceed the realm of basic care needs. That is, care is often task oriented (Armstrong-Esther, Browne, & McAfee, 1994; Kelly, 2010; Perrin, 1997; Innes & Surr, 2001) and focused on the physical needs rather than the emotional and personal needs of residents. This is at no fault of the staff however, since there is very little time allotted to provided care in most facilities that exceeds these limitations. This is unfortunate since these interactions have the potential to benefit the resident's quality of life by allowing them to feel important and a sense of self worth. Being shuffled along to get dressed and toileted in a factory-style manner is not a healthy or positive way to experience every day life. Parbury et al. (2012) note that workers are often too focused on the completion of tasks such as personal hygiene and feeding. As a result, sometimes they may unintentionally forget to consider how the individual resident is experiencing the tasks. The residents in these situations fall at risk of de-personalization and care that does not meet all of their individualized needs. Staffing issues may also play into the lack of time for personalized care. Understaffing will mean rushing care that is less personalized. This is concerning since rushing has been known to be a risk factor for assault (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Finding ways to improve staffing levels may assist in reducing workload demands and allow staff to spend more time with each resident. In turn, the risk for assault will dissipate (ibid) and staff will experience less frustration resulting from the inability to provide the care they want to provide to their residents.

Staff are Unhappy About Access and Options for Education and Training

In long term care, it is not unusual for both special care unit and non special care unit staff to perceive barriers to receiving adequate training in dementia care. Approximately one third of special care unit staff and half of non special care unit staff in a study conducted by Morgan et al. (2012) revealed that they had not attended any continuing dementia workshops or training of any kind. Many direct care staff expressed dissatisfaction with their access to dementia care training and described some barriers to accessing training. Barriers mentioned in this study included but were not limited to: the lack of programs in existence, staff having to attend workshops on their own time rather than during work hours, and having to cover various costs associated with registration and travel on their own accord. A potential strategy to reduce travel costs would be including on site training education programs as suggested by Morgan et al. (2012). Unfortunately, this solution still requires the availability of experts who are willing to travel to provide training as well as the resources to reimburse them for their time.

There are also several systematic and organizational barriers to implementing and utilizing dementia educational programs within long term care (Levi-Storms, 2008). Moreover, there are a lack of standards within the system for evaluating initiatives (ibid).

Training opportunities are helpful for staff to improve the knowledge and skills necessary for working with individuals living with dementia. It is important for staff to be provided with opportunities to further these basic skills since they may find it beneficial when conducting their work. In turn, there will be better outcomes for staff and therefore, for residents and family members as well. Dementia education and training has the potential to create better quality care and a less stressful long term care environment.

Communication Issues

Frontline staff provide the majority of direct care in long term care and yet, they initiate very little communication during their interactions with residents. This is amplified for residents living with dementia (Levi-Storms, 2008). The progression of dementia is often accompanied by a decrease in communication by way of many language deficits (Barbosa et al., 2014; Train, Nurock, Manela, Kitchen, & Livingston, 2005; Wang et al., 2013). These deficits include: memory loss, decreased attention span, and some impairment in judgment, insight, and abstraction (Wang et al., 2013). People in the later stages of dementia are more likely to lose their ability to communicate effectively where verbal skills are lost. This makes it difficult for staff and family members to identify the individual wants and needs of the resident and functions as a major barrier to quality care. Furthermore, where there is a combination of deficits, the potential for residents to display disruption behaviours increases (Kao, 2004; McCabe, 2004; Paquay et al., 2007; Wang et al., 2013). Education and training should be geared at developing effective communication between staff, family, and residents early on in order to minimize the occurrence of various behaviours.

Studies conducted by both Barbosa et al. (2014) and Wang et al. (2013) found that many staff are less likely to interact with residents who have dementia than with the non-cognitively impaired ones. This lack of interaction was related to the fact that residents with dementia were viewed as being less likely to speak. Care workers were also unsure about whether or not what they say to residents with dementia is being understood. Residents who have dementia receive poorer communication with staff in comparison to those who do not have dementia (Levi-Storms, 2008). This is unfortunate because individuals living with dementia require purposeful communication in order to receive quality care but are less likely to be recipients of it (ibid). The result of these language issues are barriers for staff and family members to provide quality care. Training must be geared towards enhancing communication between staff, family, and residents.

A lot of people feel helpless in caring for someone who has dementia. In particular, many struggle with understanding the meaning behind various behaviours and actions (Wang et al., 2013). They fail to recognize the real needs of residents and have trouble identifying where they are at emotionally (ibid). This causes barriers to care; an issue that could be improved upon with more effective education and training methods that focus on effective communication and approaches. Poor communication is associated with relationship conflicts and increased problem behaviours (Wang et al., 2013) and often results in poorer quality of life for residents. Effective communication strategies will benefit the quality of life of the resident. When staff are unable to comprehend the verbal or nonverbal behaviours of residents, a vicious cycle occurs (Wang et al., 2013). Staff are forced to repeat themselves often when residents forget or are unable to understand what is being asked. This results in a high level of frustration and stress for both parties. As a result, the resident's wants and needs may go unmet. Learning how to identify the meaning behind verbal and non verbal cues from residents or decoding, "blocked messages" (Wang et al., 2013) is an important element to include in dementia education and training programs. Moreover, communication strategies that assist in understanding the cognitive and emotional needs of residents living with dementia will encourage the retainment of their personhood (ibid).

Family members are also affected by communication issues. Many may feel left out in some aspects of care which can negatively affect their well beings. The stress of having a family member living with dementia can be amplified as the lines of communication begin to deplete. Families may become frustrated in knowing that the resident may have unmet needs. Furthermore, families may feel out of the loop in the care of their family member if staff are not trained to keep them informed and maintain lines of communication. Previous literature has noted that many families wish to be more involved in the care of their families living with dementia in long term care (Moriarty & Webb, 2000; Naleppa, 1996; Simpson & House, 2002; Train et al., 2005). Knowing this, it is important to develop improved communication lines between staff and family members and not just between staff and residents. Involving family members is a beneficial tactic in order to amplify the chances of meeting the needs of the residents in long term care. Families will be able to voice their concerns and make suggestions for care approaches with staff. This type of dialogue is beneficial as it may ultimately lead to the better treatment and care for the residents. Education and training methods should involve a piece on how effective communication is beneficial for all parties. It should also teach staff how to properly implement any suggestions for more effective communication.

Pain Management Issues

Another issue that surfaces among the literature and pairs well with communication issues mentioned, is proper pain management of residents living with dementia. Poor training of staff leaves them less likely to be able to understand and notice when residents with dementia are in pain. Pain is often under assessed and under treated in residents who have dementia (Liu & Lai, 2014) because of communication issues. The prevalence of pain ranges between 45% and 80% older adults in the general population and increases further for residents living within long term care facilities. In long term care, pain levels may affect as many as 83% of those living in the facility (Leone, Standoli, & Hirth, 2009).

Specifically, when older adults with dementia experience unpredictable and variable decline (Regan, Tapley, & Jolley, 2014) they may not be able to clearly communicate their wishes or notify staff and family when they are in pain. This can lead to the underassessment of pain among residents and is a major barrier to end of life care. Unrelieved pain can have negative outcomes on residents and staff. It can lead to behaviour change, social withdrawal, agitation, a lack of sleep, irritability, aggression, among other poor care outcomes. Regan et al. (2014) highlight effective pain relief as being one of the main priorities of end of life care for residents with dementia. They suggest that the development of pain assessment tools is important. Leone et al. (2009) note that assessing pain in this population is challenging due to the complexities of communicating and the combination of physical pain, depression, loneliness, sadness, anger, etc.

Self report measures are the most frequent pain assessment tool but may prove to be too difficult to utilize among a population of residents living with dementia (Liu & Lai, 2014). Some residents may no longer be able to fully communicate their needs or may be misinterpreted by staff who are attempting to communicate with them. Wishes may not be understood or interpreted inappropriately, resulting in poorer care quality. It is important for staff to be trained on how to pick up verbal, physical, and behavioural cues that may be linked to pain. Sometimes the behaviours being displayed by residents are merely attempts to communicate needs. Establishing a standardized pain assessment tool or program may be a difficult task (Leone et al., 2009) but there is still a need to consider how to best understand how residents display pain in order to improve the quality of care provided and the quality of life of the resident in pain. The literature also noted that accurate pain assessment, knowledge of pain and behaviours, and beliefs and attitudes of staff play into some of the barriers to provided better quality care (Ghandehari et al., 2013). Furthermore, some staff are not aware of all pain assessment measures that currently exist (ibid). Education on these measures will be paramount to achieving more desirable care outcomes for residents living with dementia in long term care.

Family Members

It would be a mistake not to include family members in the realm of individuals affected by insufficient dementia education and training for long term care staff. There are parallels in the experience of caregiving of staff in long term care who are paid and with family caregivers who are at home. These groups are similar in terms of feelings of stress and difficulties in coping with problem behaviours associated with dealing with individuals who have various cognitive impairments associated with dementias (Logan, 1997; Moniz-Cook, Woods, & Gardiner, 2000;

Train et al., 2005). Furthermore, when caring for an individual stops in the community and they are placed into care, family members will be at a higher risk for experiencing various stressors. This is because research has suggested that the caregiving role does not cease to exist upon admission into a long term care facility (Train et al., 2005). Though caregiving dynamics may change, there is often continued involvement in individual residents care (Mullin, Simpson, & Froggatt, 2011; Zarit & Edwards, 2008). Having a family member who has dementia is stressful no matter what, but potentially more stressful when the primary caregiving role is placed into someone else's hands.

Dissatisfaction of families is related to a wide range of other considerations (Train et al., 2005). Family members who are confident in the care their families are receiving are likely to be more satisfied than if they feel their families are receiving substandard care. In one study, comments from relatives often revolved around the concern that their family members are not receiving the best possible care they could be receiving. Similarly, despite family members' tendencies to be quite positive about the staff in long term care facilities, some feel unable to communicate their concerns because their relatives are vulnerable (Train et al., 2005). There also seems to not to be appropriate channels of communication for them to do so within these care settings (ibid) which creates additional stress for families. Trusting staff who care for these individuals is important and family members need to feel as though their families are in good hands. Furthermore, being able to remain actively involved in the planning of care of residents will have a direct effect on family satisfaction. Train et al. (2005) discuss how sometimes family members do not view themselves as equal partners in decision making regardless of certain policies that state that they are entitled and should be involved in regular reviews and and actual care planning. Where staff are not trained to communicate effectively, family members may feel left out which may create additional unnecessary stressors.

Family members who are unfamiliar with dementia or the progression of the disease may also benefit from education centralized on dementia. Understanding what is happening to the individual may assist them in handling the situation better and aid in better care planning for the individual living in long term care.

The Need to Develop More Person Centered Care

According to Kitwood (1997), the care environment needs to be informed by a person's social and functional history rather than just by their clinical history. The environment must be adapted to enhance individual residents rather than focusing on their deficits. Care facilities that support the individual resident's needs will enhance their well being by making them feel a sense of value or worth. These needs include their need for love, affection, attachment, identity, and inclusion. The incidences of disruptive behaviours will see a reduction in these facilities where person centered care is implemented (Brooker, 2007; Parbury et al., 2012; Slater, 2006). Some common aspects of person centered care are: attempting to maintain personhood of those cognitively declining (Normann et al., 1999); individualizing care and the environment (Post, 2000; Normann, Asplund, & Norberg, 1999; Ettema, Dro¨es, de Lange, Mellenbergh, & Ribbe, 2007); prioritizing relationships as much as care tasks (Sjo¨gren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2011); and involving family members in decision making (Sabat, 2005; Hughes, Lapane, & Kerse, 2011; Van Der Steen, Van Soest-Poortvliet, Achterberg, Ribbe, & De Vet, 2011; Sjo¨gren et al., 2011; Terada et al., 2013).

A lack of person centered care is a majority contributor to the difficulties experienced by nursing staff in long term care (Parbury et al., 2012; Passalacqua & Harwood, 2012; Wang et al., 2013). Personal information is helpful for staff. It helps them develop a greater understanding of the resident and the life they lived prior to developing the disease and requiring formalized care interventions. Learning more about the residents also helps improve the delivery of care to residents and encourages more effective communication during care routines (Brown Wilson et al., 2013). Several studies also noted that person centered care has the potential to reduce the use of physical and chemical restraints on residents (Fossey et al., 2006; Werner, Cohen-Mansfield, Braun, & Marx, 1989; Parbury et al., 2012; Seigler et al., 1997). This is extremely beneficial as sedation should be one of the last possible resorts when dealing with an individual living with this disease.

A person centred approach is not easy to sustain in the care of people with dementia who display a wide range of needs, emotions, behaviours, and responses but that does not mean it is impossible to provide person centered care to these residents. The possibility to incorporate the selfhood framework into staff training exists and doing so has the potential to transform the experiences of people living with dementia (Kelly, 2010). The personhood of residents with dementia can be fostered by taking part in interpersonal interactions between staff and residents (Parbury et al., 2012). If staff are educated about how to recognize and support verbal and visual expressions of the self of people with dementia, it may promote better engagement between the two and encourage staff to view residents as having purpose (Kelly, 2010). More meaningful interactions will also be fostered though this approach (ibid). A lack of efficient and lengthy enough training will result in a lack of skills needed to communicate effectively with residents in a purposeful way.

Barriers to Person Centered Care

There are many barriers to developing person centered care in long term care. Time constraints, staff stability (Passalacqua & Harwood, 2012), and communication issues all play their roles in creating issues. Providing personal care is not viewed as being a very glamorous or prestigious job (Innes 2002) and staff hold little influence in politics. Having little influence in the workplace impedes their abilities to make changes (Kelly, 2010). The interactions residents have with nursing/direct care staff are also much different than the interactions they have with other staff members in long term care (Kelly, 2010). Direct care staff are strapped for time frequently which results in interactions being restricted to providing basic care alone. This makes it extremely difficult to develop a good personhood framework. Direct care staff need to be frequently involved in the development of education and training programs. By taking their opinions into consideration, educators will be able to see where some current issues are. From here, they may utilize staff opinions to develop the best possible training regime they can that will have the most positive effect on staff, family, and residents.

Choosing to intentionally or non intentionally exclude family members in care affects the quality of lives of the residents in negative ways. Families can be extremely helpful in assisting staff how to understand the personhood of individual residents. They are the ones, after all, who best understood what the person was like pre-disease. It is important to distinguish how to negotiate with family caregivers to increase their involvement in care (Bramble et al., 2011) in order to develop person cenetered care in long term care. In particular, spouses have the potential to continue being a large part of the resident's sense of self (Gladstone, 1995). Dismissing them or any other family members from care, is a major barrier that can affect the quality of lives of residents and leave them feeling left out. Family members who do not know how to deal with individuals with dementia is also a care issue. They need to receive opportunities for dementia education and training so that they may remain active members in care for residents living with dementia in long term care. The education associated with the FIC (family involvement in care) intervention introduced by Bramble et al. (2011) improved family knowledge about dementia. It also assisted in how to raise the family's involvement in the care of their family members. It is worth seeing whether or not other interventions like this currently are being offered in long term care and whether or not family members in Winnipeg, Manitoba feel as though this would be beneficial for them.

Residents also need to be involved in their care. Too often, when dementia is introduced, residents become almost like non-people. Their opinions become dismissed and considerations of their wants and needs are not taken as seriously as they should be. This, in itself, is a major barrier to achieving quality care in long term care. They are still people who lived lives. The disease does not define the person and continual awareness and being reminded of this is crucial in order to develop more person centered care approaches. Staff and family need to involve the residents in their care where possible and provide them the opportunity to remain actively engaged in their care where possible.

Summary

The intention of this chapter was to provide some information on how dementia education and training for staff and families is important for achieving successful dementia care.

It was also meant to review the benefits education and training has on staff, families, and residents as well as highlight the need to continue developing this area of dementia care. As the population continues to grow and more people living in long term care have dementia, the more important it will be to provide staff and families with a well rounded education about dementia care approaches and issues. Within the literature, several issues with current education were discussed. These included insufficient training to meet the needs of staff, inconsistent training, a lack of regional standards in training, and some content issues with training offered. When staff are not educated, they suffer, the residents suffer, and the families suffer. Staff members are under time constraints that may sometimes interfere with proving quality dementia care that is person centered. They also have heavy workloads and are under staffing pressures that create a stressful environment. Families may sometimes feel left out in the realm of communication between staff and themselves and do not always view themselves as equal partners in decision making for the resident. This causes stress for them as well. Lastly, residents who live in these facilities are under their own kind of stress and they are extremely vulnerable in situations where their care is being placed into someone else’s hands. In order for them to receive a higher quality of life and care, residents need to have staff members who are educated providing person centered care, and families who are included and understanding in their lives. Furthermore, ageism is important to consider when it comes to individuals who live with dementia as this form of discrimination may sometimes be present in social structures including long term care facilities. By continuing to address the current strengths and weaknesses in care and education and training provision, residents in these facilities will receive better care and staff, families, and these residents will experience better outcomes overall.

CHAPTER TWO: METHODS

This chapter outlines the methodology that guided this research on staff and family member's perceptions about the strengths and gaps in the current dementia education and training that is provided for long term care workers and families. It outlines the qualitative research methods used in this study. Each sub-section describes the design of the study and is followed by a detailed description of the qualitative research methods, data collection and analysis, and the research rationale. The chapter will conclude with the research analysis procedure.

Qualitative Research Methods, Assumptions, Data Collection, Analysis and Rationale

Qualitative Research Methods

Qualitative research is essential to any researcher who is interested in establishing an understanding of a phenomenon through the eyes of those directly affected by it. I am a firm believer that in order to understand a phenomenon in its entirety, one needs to talk to those who are affected most by it. People are the key to understanding issues about people. My personal feeling is that in order to understand how to fix or begin to understand issues that affect people, one needs to speak to the individuals at the heart of the phenomenon. Qualitative research tends to focus on making an effort to generate situational descriptions and interpretations of phenomena (Stake, 2010) rather than focus exclusively on numbers. Qualitative data may have several interpretations that lead to several forms of understanding and leaves room for several forms of understanding. For these reasons, qualitative research approaches were well suited for this study.

This was a qualitative study involving thematic content analysis that took place in one long term care facility in the Winnipeg, Manitoba area. Through an analysis of both audio, written transcripts, and interviews as a whole, common themes were identified and coded into sub themes to form a greater understanding of the issue at hand. The research focused on exploring phenomena from multiple perspectives through the use of various methods. This began with the analysis of the interviews, in particular the actual spoken words and their underlying meanings. The purpose of this study was to explore the current status of dementia education and training within long term care facilities with one specific setting as an example. Using content analysis in this case, functions as a way to understand what has or has not been done to further the develop dementia education and training in long term care settings by identifying common trends in the responses of participants.

The Role of the Researcher And Assumptions

According to Raymond Madden (2010), every qualitative researcher will approach projects differently as a result of having an individualized background and set of experiences. Individuals are shaped by all facets of who they are (by their gender, age, culture, etc.) and it is these traits that individualize the researcher’s approach and experience of a research project (ibid). A qualitative researcher needs to be mindful of this when considering how their experiences will reflect on their roles as a researcher. They must reflect on how they feel and who they are as this will affect their ability to conduct their research (Pillow, 2003). The ability of the researcher to demonstrate reflexivity is important and in order to be reflexive, one must try and balance objectivity and subjectivity (Madden, 2010). Madden (2010) cautions that subjectivity can be dangerous and a researcher needs to be able to identify and manage their position in regards to their research in order to represent it properly. It is the researcher's background and knowledge about an area of interest that will affect the ways in which a phenomenon is represented. This raises questions about bias in research. As Stake (2010), noted in one of his works, "bias is ubiquitous" (p. 164). Bias is found everywhere and though sometimes undesirable in research (ibid), there is no avoiding having some researcher bias within a study. With this, it becomes important to balance appropriate subjectivity and reflexivity within the research and try to, "recognize and constrain our biases but go further to check the data gathering and analysis with validation" (Stake, 2010, p. 166). In my research, I had to be certain that I bracketed my opinions in order to remain open to staff and family member's opinions. What I mean by this, is that I needed to be mindful to keep my own opinions about where I thought education and training should improve to myself and not influence participant's responses by discussing my own opinions with them in the interviews. In doing so, I believe that the research findings reflected an accurate view of the participant's views and opinions. It is impossible for a researcher to remain completely objective but bracketing allowed me to be in a better position to appreciate the phenomena from the participants' points of view. Subjectivity can be an issue in cases where the researcher feels a strong connection with what they are studying. There are several ways of knowing, interpreting knowledge, and representing ways of knowing in research. On the topic of subjectivity in research, I believe the background and subjectivity of the researcher will strengthen what they and the participants feel is important in the representation of the data. After all, one of the researcher's key roles is to present the data in a way that will get the point of the participants out there, as well as their own.

One-on-one in person interviews were used as a means to unveil what beliefs staff and family members of residents living with dementia in long term care have about the current provision of care. During them, I needed to be mindful of my place as a researcher in the setting and continually evaluate my position throughout the process to ensure that I was within the scope of where I needed to be. A challenging part of research is knowing where you fit in terms of subjectivity. How much is too much? How little is too little? I needed to be conscious of reflexivity in order to now be able to produce a final representation of my findings as much from the perspective of the participants as possible. In order for those reading to understand why I needed to be mindful of my positioning, it may be best to relay my prior experience as a Health Care Aide in a long term care facility.

My Location as a Researcher

Since May, 2011, I have been employed part-time in a long term care facility in Kenora, Ontario. I travel to and from when I can and have spent the past six summers living in Kenora, Ontario while working there. I have been able to work directly with individuals living with dementia myself and see first-hand that there is a direct need to continue developing and offering education and training for staff and family members. This job has given me great perspective. I understand the day to day struggles of the care workers who want to provide care but face barriers and I witness the struggles of the residents who are cared for. I see the pain and heartbreak the family members endure when they visit. These are all experiences I would not have understood fully, had I not been given the opportunity to be placed in a direct care staff's place in long term care. It is not a matter of not caring about providing better care to the residents as it's that there are many barriers that get in the way of providing better dementia education and training. I think that the simple awareness of there being training is lacking and workplaces need to prioritize this more. In the time that I have been employed there, I have very seldom been made aware of or offered training options to enable me to provide better care to deal with residents living with various stages of dementia. Furthermore, the training that has been offered has been limited. Other staff there have also expressed their desire to be offered more education and training on dementia care as they are not happy with what little is being offered. This breaks my heart because at the end of the day, it is the residents who suffer. Over the years, I have seen some staff approaching people in inappropriate ways; becoming aggravated with someone who is not listening well or infantilizing the residents with the use of patronizing language. I have also seen some staff who are wonderful with the residents who have various dementias. I do not mean to speak ill of my co-workers in any way. They are wonderful people and that is not my intention. My intention is to address the fact that some people do not fully understand how to interact appropriately with individuals living with dementia. I firmly believe that most of my co-workers have great intentions and that the ones who do have trouble would benefit from understanding the disease better or by being given the tools to more appropriately care for these residents. These residents are unique and need to be cared for in different ways on an individual basis. Their dementias are not all the same and thus, they require a multitude of differing approaches to care. I can tell that some staff members truly care but are unaware of how to handle these residents. I have seen other staff who appear uncomfortable, non-compassionate, or lost in the management of care for some of these individuals. I, myself have experienced a fair share of trials and tribulations in dementia care. These are all issues that could be improved if education and training on dementia was prioritized more in long term care. In fact, there seems to be an informal standard of on the job training in place for workers which doesn't benefit anyone. Yes, some things cannot be taught in a book alone but it is not fair to throw a worker with no prior dementia education or training or even a basic understanding of the disease on the unit floor and expect a good outcome. The staff, the residents, and the families suffer when this is done. We must give workers the tools they need to care for this population and relying primarily on hands on training isn't the answer to the problem.

I have always been passionate about learning about aging even if at first, I didn't realize I could make a University career out of it. As a young child, I spent a lot of my time with older people. In particular, I spent countless hours with my mother's mom who over time, developed Alzheimer's disease and passed away shortly after having experienced a fall and subsequently, a broken hip. I witnessed her struggle at a young age and have witnessed many others struggle through my work now. All I want to see, is better care provided to these individuals because they are people just like myself. They have lived lives and have accumulated their own memories over time. They deserve to spend their final years receiving the best possible care that is available. This is not possible without adequate dementia education and training.

Practically, I knew that I was entering this research with a goal in mind. I knew that I wanted to see change in the provision of care to older adults living with dementia in long term care. I knew that this would have an effect on my journey as a researcher and have the potential to affect my direction. During the process, I made myself open to to alternative truths that were revealed in the data. I was flexible and did my best to bracket my opinions when exploring the results of my interviews. I have certain ideas about where education and training is lacking and where I think it can be improved. My research has revealed some similarities but also, that participants see alternative avenues that need to be addressed that I have not considered. I think that being a good researcher in practical terms simply means following your initial framework but also learning to accept that research is a process and there will be times that a researcher must adapt from their original framework. Research is not black and white and the findings in a field will never be certain or absolute.

Ethical Review Process

Prior to the collection of data, an ethics protocol was submitted to the Joint Faculty Research Ethics Board for approval. In order to ensure the confidentiality of the subjects, pseudonyms were used in the final writing of the thesis. Interviews were scheduled in such a way as to avoid the potential for participants to see each other between the ending of one interview and the start of another. All research materials including audio tapes, transcripts, consent forms, and hand written notes were stored in a locked room, accessible only to the researcher (myself) and supervisor. Further, any data stored on the researcher's computer was only accessible by the researcher as it was encrypted. Informed consent was provided by utilizing a written form. Opportunities for each participant to read the informed consent form and ask the researcher/ facilitator any questions prior to confirming their participation was provided. The informed consent form included the following information: the purpose of the study and subsequent details, procedures that were to be used, risks and potential benefits of individuals choosing to participate, details surrounding confidentiality and rights of participation and withdrawal. Participants were free to ask any questions regarding participation prior to, during, or after the interview This study complied with the requirements set forth by the University of Manitoba's

Research Ethics Board. The certificate of approval is attached as Appendix A. The consent form is attached as Appendix H.

Qualitative Data Methods Inclusion Criteria

Recruitment/Choosing The Research Site

A variety of recruitment methods were used within long term care facilities in the Winnipeg, Manitoba area to obtain participants for this study. The initial mode of contact involved the distribution of an email which was to be sent out to the Directors of Nursing within selected long term care facilities or relevant persons or via telephone call if an email was not available. This email contained information about the study and invited the facilities to participate. Several facilities were contacted and it was initially anticipated that the participation of two to three facilities would be sufficient to provide rich data for the study. The two facilities that were in agreement to participate and that matched my selection criteria were to be chosen to be involved in the study. Unfortunately, due to some recruitment issues and because there was an accreditation process that homes were taking place in, only one facility was recruited for the study. The goal was to interview between 5 and 7 individuals within each facility and have at least two of those individuals be family members, with the remainder being staff participants. Participants were to be either be employed within the nursing department of the long term care facilities (personal support workers, RNs, or managerial staff members in charge of providing education and training to staff) or to be a family member of a person living with dementia in long term care. In the end, thirteen participants took place in my research within one facility.

When the selected facility expressed interest in my study, I was asked to complete a separate ethics review for that facility. The process of review took nearly a month but consent was obtained. Upon approval a contact person was provided to aide the researcher in recruitment. The original plan was to distribute posters and contact participants directly through in facility visits, emails, etc. The facility decided that it would be better if I was provided a contact person to aid me in beginning to talk to people. A meeting was then set up with all of the unit managers of the facility where a presentation on the intended research was given, followed by a question and answer period. Unit managers were given my contact information and asked to get in touch should they be interested in getting their staff and family members involved. Some managers were interested in helping find staff and families as well as being interviewed themselves. Prior to each interview, consent forms and demographic information forms were sent via email and participants were given the opportunity to ask any questions they had before scheduling a formal interview time. Once those interviews were scheduled, unit managers introduced me to some staff and family members periodically. At that point, I gave them information on my study as well as my contact information. Interested individuals were asked to contact me to talk more about the study or to set up a time convenient to them to schedule a formal interview. Again, all participants were given consent forms and demographic forms ahead of time and interviews were scheduled accordingly. They were free to ask questions at any time or withdraw from the study at any point if they were no longer interested. All interviews took place in private areas within the long term care facility at times convenient to the participants.

Criteria for Qualitative Sample Selection:

Originally, two long term care facilities were going to be chosen to to recruit participants and collect data from for this study. Eligibility criteria included that each long term care facility needed to have a specialized care unit for older adults living with dementia. Participants needed to be either direct nursing staff or a family member of a love one living with dementia in the facility. Upon receiving consent to recruit in that facility, recruitment of nursing staff and family members for the study began. A contact person was given to assist with speaking with unit managers about the study in a formal meeting. At that point, contact information was given for the managers to utilize if there was interest in participating. Managers then passed along the information to workers and family members about the study and were given the researcher's contact information. They also guided me around the individual units and introduced me to different people. Interested individuals who contacted me were selected for the study based on a first come first serve basis. It was my intention to interview between five and seven individuals (at least two family members and the remainder staff) from two long term care facilities in the Winnipeg, Manitoba area for a combined total of 10 to 14 participants. However, as I stated previously, only one facility was obtained for participation and so, 13 participants were interviewed within that facility. The participants included: three managerial staff members, two Clinical Resource Nurses, three Health Care Aides, and five family members across three separate units. A detailed description of the participant demographics will be discussed next.

Participant Characteristics

A total of thirteen participants were interviewed for this study and included the following sampling characteristics: three unit Mangers, two Clinical Resource Nurses, three Health Care Aides, and five family members. All of the participants were asked to complete a brief demographic form before the interview began. These findings may be found attached as Appendices D1 and D2 at the end of the document. The social characteristics questions for staff asked about their age, self-identified ethnicity, and highest level of education and other courses or training. The work-related questions asked about their experience in the job, including number of years working in their current position. The social characteristics questions for families asked about their age, self-identified ethnicity, and highest level of education and other courses or training. The work-related questions asked about their current work status.

Of the three unit managers, two worked in dementia-specific behavioural units and one in a chronic respiratory care unit in which some residents with dementia did occupy rooms. They were all female and ranged in age from 25-54 years old. They were not asked to provide their exact ages. All three identified as Canadian. Two of three were in domestic partnerships or married and the other, single. Two were relatively new in their positions, working in them for 1-5 years while the other has been in the 11-20 range.

One male and one female Clinical Resource Nurse were interviewed, each of which occupied their roles on dementia-specific behavioural units. Both identified as Canadian. One person identified as being separated and the other, divorced. Years working in the position varied greatly between the two with one individual having been in the position for 1-5 years and the other 21-30 years.

Three Health Care Aides were interviewed for this study. All three Aides were females between the ages of 45-64 who identified as being Canadian and in married or domestic partnerships. They were not asked to provide exact ages. Of the three women, two had been working in their positions for between 21 and 30 years while the remaining participant identified being employed as a Health Care Aide for over 30 years.

All five family members who were interviewed for this study were females. Four of the five identified as being Canadian and one identified as being English. One of the five women was between the ages of 55 and 64, two were between the ages of 54 and 74, and two were ages 75 or older. Four of the participants were retired and one was working for wages.

To summarize, the profile of the thirteen individuals who participated in this research depicts a diverse group varying in both age and educational standing with the majority being of Canadian descent. All staff have achieved varying levels of certification for their positions and are generally long-term employees. The family members also represent a diverse group in both age and educational backgrounds.

Below is a series of charts that outline these participant characteristics in relation to which specific participant they belong to. It may be useful to reference while exploring the findings of this study and specifically when participant quotes are given later in this section. It is important to note that for privacy, all names in these charts are pseudonyms and not the actual names of participants. As mentioned above, more specific demographic information on participants can be found at the end of this document, attached as Appendices D1 and D2.

Demographic Characteristics

Managerial Staff Members					
Participant Pseudonym	*Age*	*Gender*	*Ethnicity*	*Job Title*	*Time Working in Position*
Charlotte	25-34 years old	Female	Canadian	Manager of Patient Care: Respiratory Chronic Care	1-5 years
Meredith	45-54 years old	Female	Canadian	Special Care/ Behavioural Unit Manager	11-20 years
Casey	45-54 years old	Female	Canadian	Special Care/ Behavioural Unit Manager	1-5 years

Health Care Aides					
Participant Pseudonym	*Age*	*Gender*	*Ethnicity*	*Job Title*	*Time Working in Position*
Melissa	45-54 years old	Female	Canadian	Personal Support Worker/Health Care Aide	21-30 years
Holly	45-54 years old	Female	Canadian	Personal Support Worker/Health Care Aide	21-30 years
Shirley	55-64 years old	Female	Canadian	Personal Support Worker/Health Care Aide	30+ years

Clinical Resource Nurses					
Participant Pseudonym	*Age*	*Gender*	*Ethnicity*	*Job Title*	*Time Working in Position*
Susan	35-44 years old	Female	Canadian	Clinical Resource Nurse	1-5 years
Aaron	45-54 years old	Male	Canadian	Clinical Resource Nurse/ Registered Psychiatric Nurse	21-30 years

Family Members					
Participant	*Age*	*Gender*	*Ethnicity*	*Education*	*Employment Status*
Dorothy	75 or older	Female	Canadian	High School Graduate, diploma or the equivalent (for example: GED)	Retired
Mable	65-74 years old	Female	Canadian	Bachelor’s Degree in Nursing	Retired
Cathy	55-64 years old	Female	Canadian	College Certificate	Employed for wages
Julie	75 or older	Female	English	High School Graduate, diploma or the equivalent (for example: GED)	Retired
Beth	65-74 years old	Female	Canadian	Bachelor’s Degree in Nursing	Retired

This study focused on understanding the views that nursing staff and family members have about staff dementia education and training in long term care facilities through the lenses of both the staff members themselves and family members of residents living with dementia in long term care. It was important to find individuals who met the criteria listed above because they are individuals who are affected directly by the current provision and state of dementia education and training. Interested individuals were also sent more information about the study including information on the interview process, location of the interview, and the expected duration. They were sent an electronic copy of the consent form and asked to review it before deciding to participate in the study. At that point, they were asked to contact me to arrange their interview if they still held an interest in participating.

Participant Characteristics and Shaping the Findings

When participants are not hand picked by the researcher but instead, are selected based on first interest, the sample and individual participant characteristics will be unique in one way or another and offer a uniqueness to the study's outcomes. This is because individuals are shaped by their own collective experiences and backgrounds and will bring their individual beliefs and experiences to the interviews and respond to questions with these unavoidable influences present. But how did the demographic characteristics of the participants of this study shape the overall findings? Would the findings have been different with a different demographic? These are some of the questions a researcher must consider when they are in the research process.

The staff members who participated were predominately married females who had been working in their positions or within the field for longer periods of time. Being female could shape the findings as their experience working in this type of setting could be vastly different than some males who work in the setting. For example, it would be interesting to see whether or not male staff would identify the same needs for safety and program developments or whether they would identify other gaps in the current provision of eduction and training. Further, by working in the setting for longer periods of time, these individuals may have previously been exposed to options or lack thereof for education and training that have not worked. They may also have been able to identify with how staff opportunity for education and training has progressed and be able to give insight into what has or has not been helpful over the years. Staff who have been working in the environment for longer periods of time may also feel differently about the need for education since most of their learning has been on the job. A newer staff member may feel that they would benefit from training more than someone who has already been exposed to this setting for some time. Lastly, the staff participants of this study were all educated beyond a grade twelve level which means that they likely have been exposed to assignments or projects where developing critical thinking was a necessity. This is not to say uneducated people are any less smart but rather, that their approaches to handling problems may be different than those who are use to an academic approach to problem solving.

The family members who participated in the study were all married females over the age of 55 who had taken on the caregiver role of the resident currently in care, at one point or another. Being a female caregiver may shape the findings because they have essentially been informally placed in a staff role for a point in time with their family member in care. This gives them a unique perspective and provides opportunity to see how their struggles might be used to develop and improve what education is currently available to them. The majority of the family members were retired and just over half were educated beyond high school. The unique part about this education, was that all three who were educated beyond high school, were educated in a health care field background; two retired Nurses, and one Health Care Aide. In looking at staff education and training and education for family members, these participants provided a duel perspective. They could approach the questions from both the position of a family member with someone in care and as a health care worker who has experienced the issues being explored in this study.

The findings could potentially have been a lot different with a different sample of participants however, I believe that the individual characteristics of these participants helped shape the findings of this study in a uniquely useful way.

The Interview

The interviews aimed to understand my study's three broader, key questions:

1. What training currently exists for long term care staff members in Manitoba who provide direct care to individuals living there with dementia?
2. What strengths as well as issues or gaps are perceived by staff and family members in the current provision of dementia education and training for staff members in long term care?
3. How can the provision of education and training for staff and families be improved to provide maximum benefit to the staff, residents, and family members?

Prior to the interview, there was a short period of time where participants were taken through the process of obtaining written consent (See Appendix H). They were expected to have read over the consent form prior to meeting for the interview but received an opportunity to ask any further questions before proceeding with the interviewing process. The interviews were tape recorded and transcribed and held at a location of the participant's choice. The interviews ranged between thirty minutes and an hour and fifteen minutes. Participants were notified that their participation was voluntary and that they were free to withdraw from the study at any time. As well, should they have felt uncomfortable at any point during the process, they could choose to take a break, to not answer certain questions, and in extreme or unforeseen cases of discomfort, individuals were told that they may withdraw from the study completely. Measures to ensure the confidentiality of participants were also taken.

The interview itself was comprised of open ended questions about dementia education and training. In the managerial staff member interviews, the majority of questions asked about the training currently provided to staff members (See Appendix E). They were also asked about what training they have received themselves in regards to dementia and encouraged to discuss what strengths and gaps they personally felt were present in the current provision of dementia education and training for staff and family members in the facility. For the Clinical Resource Nurses, the same guide was used but because they fall into a position in between managerial staff and direct care staff, some questions had to be adapted on the spot. In these cases, some of the questions from the direct care nursing staff guide were used (See Appendix F). The questions for Health Care Aides were geared towards identifying if they perceived themselves to be receiving adequate training opportunities and to identify what they did or did not enjoy from what they have been offered, what they enjoyed from the education and training they have had, and what they felt was missing. They were also encouraged to discuss what challenges they face on a day to day basis, and what they enjoyed about working in their positions. Family members were asked a series of questions regarding the care at the facility. Some of these included whether or not staff seem calm and approachable most times, if there were ever any issues of concern regarding the care, and if they felt comfortable in asking about any issues they may have. They were also highly encouraged to discuss the strengths they saw in the care their family members received. In regards to education and training, family members were also asked about what opportunities they had been given to receive information on dementia upon their family member's admission into the facility. If any was provided, they were encouraged to express what they did or did not enjoy and asked to talk about what types of education and training they may find to be most helpful for themselves. The interview guide for family members is attached as Appendix G at the end of this document.

Data Analysis and Interpretation

Data analysis and interpretation in this study utilized a content analysis approach. Content analysis focuses on the meaning of communications (Krippendorf, 2013) and is a form of empirical inquiry that utilizes an exploratory process to make inferences from given texts in order to produce new narratives. Margarete Sandelowski (2000) has emphasized that "qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies" (p. 338). The purpose of content analysis is to re-articulate what information is given, using higher order themes that can synthesize or summarize the data. In this case, content analysis was utilized to code and find common themes among responses from participants in order to produce common findings that may be useful in developing education and training further. I aimed to identify common themes about dementia education and training amongst the written responses of staff and family members that would allow me to see where they felt current strengths and gaps were, utilizing my knowledge of the literature also, as well as my own work experience. The process of content analysis begins by coding the data or transcribed interviews in this case. This involves reading and re-reading the series of transcripts from participant interviews while cross referencing them to the audio transcripts. The researcher identifies initial broad themes in each transcript, then reviews the text again for a secondary level of refinement.

At the rudimentary point of cross-referencing and proofing audio and transcripts, Sandelowski (1995) suggests that many researchers will begin to underline key phrases, “simply because they make some as yet inchoate impression on them” (p. 373) or ideas while making notes within the margins, “just because they do not want to lose some line of thinking” (ibid). As I underlined things that stood out to me, I began to write ideas in the margins or words that came to mind while reading. For example, when participants began talking about the safety of the staff and residents frequently, I wrote, “safety/staffing” with a question mark in the margins. Similarly, I found myself writing things like, “personhood” or, “dignity” when we began to talk about resident care and time for providing that care. In this process, the actual spoken words of respondents are coded and the researcher takes into consideration the underlying meaning of these words as well. That is, respondents may say something that has more meaning than what the words themselves imply. This is a process of combining content analysis and looking at both the manifest (actual words) and latent contexts (what those words may mean) of the data collected (Babbie & Benaquisto, 2010).

During this process I paid attention to both the written words and how they were spoken in the audio transcripts to look for a more solid idea of what the spoken words truly meant. This was important since tone and speech in general are good indicators of how a person is feeling about a subject. The researcher also refers to their research question and literature review in order to develop a greater understanding of the data collected. As I read and listened, I was always keeping in mind what brought me to this subject in the first place. Looking at my key questions prior to each analysis helped focus me on what I was trying to find.

Through a constant comparison of emerging themes, I came up with common sub-themes and concepts that appear present in the raw data. According to Sandelowski (2000), the researcher later analyzes these sub-themes in order to develop a final narrative or finding (Sandelowski, 2000). In the end, I read and re-read my transcripts and looked for common themes or responses from the participants, using peer review (my supervisor, Dr. Roger), to review and refine themes at this level. I ensured that I had looked at not only what was said, but how it was being said. Another component of latent analysis is the researcher recalling any visual cues or gestures or changes in voice intonations that took place within the interview that may be paired with the text to form meaning. As I analyzed each interview, I tried to picture myself sitting across from the participant again. I reviewed each interview guide I had to be sure I did not miss any notes during the actual interview that would be helpful for analysis. Did they behave in any way that stood out to me as unusual or helpful for this research? Was there anything that I could recall happening during that time that could be beneficial to this analysis? It is thought that this latent analysis of recalling visual cues paired with any notes taken during the interviews will aide in the researcher's ability to interpret the data and provide findings and is known as the visual and communicational characteristics to address the phenomena (Krippendorf, 2013). This process, in tandem with meetings with my supervisor to review the final themes that had emerged, to review the literature and my work experience led to the final themes.

Rigour

According to Davidson-Reynolds (1971), rigour is the use of logical systems that are accepted by scientists to ensure agreement on both the predictions and explanations of a theory that is being tested. Rigour in research is used to strengthen and prove significance of the findings of a study (Nicholls, D, & Will, 2009). For those who are more familiar with quantitative research, a qualitative approach can seem lacking in rigour (Nicholls et al., 2009; Wilson, 2003) but qualitative sampling needs equal care and rigour. Finding a qualitative sample involves more than simply picking just those who are available and willing; it has a structure as well. Depth and relevance of data must be developed (Wilson, 2003). Depending on your research question you may need to select people because they will be typical cases representing an `average' of opinions or experiences. It may also be that your research question will be best answered by looking at extremes of opinion or experience. If not, perhaps you will instead need to illustrate a broad range of opinions, covering the whole spectrum rather than chunks of it (ibid). The point is that selecting potential respondents should be logical. Each case should be considered in the light of what they might add to the research as a whole. It is purposive sampling, not haphazard or convenience, and requires careful planning and attention to detail (ibid). Rigour was achieved in this study by attempting to fully exhaust the data in the representation of findings. This was done through the use of exhaustive qualitative interviews. The findings of the study were considered sufficient once it became clear that the same themes were surfacing across all interviews.

Reflecting on Braun & Clarke’s (2013) model, rigour was also achieved by attempting to make the research and data reliable, valid, generalizable, and transferable.

Reliability. Good research must be reliable in nature and contain the possibility of generalizing the results to different groups. Reliability in qualitative research refers to good quality achieved through consistency in the research process (Braun & Clarke, 2013). It refers to the potential for research outcomes to be repeatedly generated by different researchers in similar settings or within similar areas of study. Qualitative research is quite variable and may be interpreted differently by different researchers (ibid) and so, reliability may become a more difficult measure of good qualitative research. However, if the view of reliability is shifted and thought of in terms of trustworthiness or dependability, it becomes much easier to use as a judgement criteria for good qualitative research (ibid). This research underwent various quality criteria and techniques to ensure reliability. This included member checking (to be discussed below), triangulation from different standpoints to develop greater analysis of the data (Lincoln & Guba, 1985), transcription, coding, and analysis. In doing so, the study achieved a greater quality control (Braun & Clarke, 2013) and therefore, produced more reliable results.

Validity. Research needs to prove what it claims to show (Braun & Clarke, 2013). A good indication of quality research is that it captures the reality of the issue (ibid) and that the results display the accuracy of this reality. The aim of this study was to identify strengths and gaps of dementia education and training in long term care. The participants confirmed the fact that the issue needed to be addressed through their responses. To be a valid piece of research, data collection needs to happen in a professional way, one that protects the participants as well as keeps the researcher’s biases as distanced as possible. Participants in this study held the right to have their identities protected and interview questions were not structured by the researcher’s biases. They remained objective and open and did not aim to guide participant’s responses.

Research also needs to undergo a process of member checking (ibid). This is the process of checking with participants to determine that their responses and the analysis accurately represent how they feel about the research question and is an important piece of validity. Participants of the study were invited to be actively involved at all points and were encouraged to make sure all the information presented was what they wanted to say. They were free to change responses at any point in time. I invited participants to receive copies of their transcripts following their interviews in case they wished to review or change anything. They were also given an opportunity at the end of the interview to add to or change any of their responses before we finished. Furthermore, I encouraged them to email or phone me at any point in time if they thought of something they wanted to share or if they wished to change their mind about being more involved. All participants declined being actively involved through the process of analysis but all but one requested a copy of the final thesis once completed. In other words, they did not wish to receive the transcripts for review, or to have any information about the study until it was fully completed. Braun & Clarke (2013) describe this process of inviting participants to be actively involved as member checking as a necessary quality control measure. It was important that my study provided valid and accurate results in order to proceed in a manner to best improve the current dementia education and training offered. I feel that I was as open with my participants as I could have been and emphasized that their involvement was welcome at any time during the process.

Generalizability and Transferability. Probably the most important piece to ensure quality and rigorous research is ensuring that results are generalizable and transferable from one point to another. It is important that the results of this study be transferable or at least in part, generalizable to other long term care facilities in the Winnipeg, Manitoba area. This will aide in achieving more consistent research. Consistency refers to the degree to which findings would be replicable in similar settings if the inquiry was repeated (Lincoln & Guba, 1985). In other words, if the same study was conducted in a different set of facilities, it would be consistent if the findings in both studies were similar. For this research study, it was believed that many of the education and training issues in one facility will be similar in another. Though training is not synonymous from one facility to another, it was believed that it is safe to assume the lived experiences of staff, families, and residents on this topic will be similar regardless of the particular care facility setting. There is little point to doing research if the results cannot be used to shed light on problems in similar areas of the topic being studied (Yardley, 2008). The results of this study may be very useful when looking at what can be done in the future in terms of research and other directions the facilities themselves may take in order to move forward in improving the current state of dementia education and training in long term care. Suggestions for future directions and research will be discussed in later sections.

Qualitative Research Rationale

The data collection procedures outlined here reflected the research and work suggested by Babbie & Benaquisto (2010), Braun & Clarke (2013), Davidson-Reynolds (1971), Creswell (2013), Krippendorf (2013), Lincoln and Guba (1985), Sandelowski (2000), Wilson (2003), Yardley (2008), and Yin (2009). Understanding the different emphasis each one of them placed on different aspects of qualitative research was extremely helpful in guiding this research study from the beginning stages to the end stages. The work of Stake (2010) and Yin (2009) on qualitative research methods was helpful in informing the researcher about different frameworks available for researchers to use and ultimately, in deciding what methodology best suited the aim of the study. Since the focus here was to explore the current dementia education and training within one particular setting, the use of thematic content analysis was very appropriate. The methods surrounding content analysis and interpretation laid out by Krippendorf (2013), Lincoln and Guba (1985), Sandelowski (2000) and Wilson (2003) were extremely helpful when the time came to understand the data and to begin to look for what needed to be said about the topics being addressed. Understanding the importance of both validity and reliability, trustworthiness and transferability of the data was made clear through the combined works of many of the researchers listed in this section. When looking at the raw data, it became clear that in order to produce findings that could be useful for future research or directives, one had to pay close attention to not only the manifest or raw content, but also to the underlying meanings or latent context. The result, was a culmination of findings that demonstrate true significance to the topic of dementia education and training in long term care.

This chapter presented information on the qualitative research methods employed in this research. Qualitative data collection and analysis methods were explained and a rationale for using these methods was provided. The chapter is a representation of the process this research study took in attempting to form findings through extensive analysis. The process of analysis for this study was based on a thematic/context analysis approach and followed the theoretical frameworks and guiltiness set forth by researchers highlighted within this section. The following section is a presentation of the findings of this research study based on this methodology.

CHAPTER THREE: FINDINGS

This chapter will present the findings from the interviews staff and family members participated in. The interview questions focused on the perceptions individuals had on the current provision of education and training for staff members and the satisfaction of overall care quality within this particular long term care facility. There will also be a discussion about how the findings do or do not coincide with the current literature on the topic of staff education and training. Complete interview guides with specific probes and questions may be found at the end of the document as Appendixes E, F, and G.

Findings

This section will be broken up as follows: A summary of the main forms of training currently offered within the researched facility will be presented followed by a discussion about the strengths and gaps in education and training that were identified by participants. This will be followed by an in depth discussion about how participant's responses to the general interview questions contributed to answering the broader, key questions. The chapter will conclude with a discussion of future suggestions and directions that may be explored in order to provide better provision of dementia education and training.

Training that Currently Exists for Long Term Care Staff Members in Manitoba who Provide Direct Care to Individuals Living There with Dementia.

To begin exploring this topic, it was important to first identify what specific programs or training modules were being made available to the staff and family members in this facility. Below, is a chart summarizing the training mentioned throughout the interviews that was or is currently available at this location:

Current Education and Training	
General Orientation Package	When staff are hired, they receive a general orientation booklet that includes a list of modules on dementia topics for completion. These include readings and videos and include subject matter such as how to bathe a resident with dementia and behaviour mapping.
P.I.E.C.E.S (More information at: pieceslearning.com)	A provincial learning strategy aimed at equipping individuals with the information and tools they need to manage people with complex mental health needs. It includes detailed information on the different types of dementia, medications, and approaching someone with dementia accordingly. This is currently offered formally to Nurses in a four day session. The facility has informally adapted P.I.E.C.E.S for a one day Health Care Aide session with the approval of the Alzheimer's Society.
Non-Violent Crisis Intervention (More information at: crisisprevention.com)	Offered in the past, this course's main focus is to provide staff with the tools needed to defuse hostile or violent behaviour in the early stages and equips them with different strategies to manage violent behaviour and teaches them safe holding techniques that they may use.
Excellence in Dementia Care	This informal course was offered at the time when a newer dementia care unit was being opened at the facility. Staff were briefed on different topics on dementia and prepared for their new roles in this unit. This was offered to all staff that worked on dementia care units.
Prevention is 9/10ths of the Law (More information at: wrha.mb.ca)	Offered in the past, this course teaches practical tools for the prevention and management of aggression.

Current Education and Training	
Dignity in Care (More information at: dignityincare.ca)	This workshop aims to teach staff how to maintain dying residents' dignity and to address their suffering accordingly at the end of life.
Other, Non-Formal: Blue Dot Program	The Blue Dot Program involves the placement of a blue dot sticker outside of more aggressive or challenging resident's rooms to notify any incoming staff, family, or outsiders that the particular resident is in need of a specialized care approach. It acts a safety measure so that the resident may be approached accordingly, with less risk of harm.
Other, Non-Formal: Family Support Group	This informal meeting occurs once a month for families of residents with dementia to receive support/ask questions and to receive education on differing topics related to dementia that are presented by staff from the facility. Topics in past have included: oral hygiene and death and dying.
Alzheimer's Society Conferences (More information at: alzheimer.ca/en)	Conferences open to the public that cover a wide range of topics on dementia and feature various public speakers.

It should be noted briefly, that prior to being hired at this facility, staff must complete courses or degrees necessary for their jobs. For example, Registered Nurses are to have a Bachelor in Nursing, Health Care Aides must take the Health Care Aide course, and so on. Prior education is important to consider because educational program content may vary based on origin of study, what professors deem as more or less relevant, and so on. This has the potential to affect the amount of content on dementia a person is exposed to, prior to working in an environment like this. This will be discussed further in subsequent sections. After speaking with staff, it became clear that a few educational and training options were available at one point or another. These included a general orientation that covered basic topics like how to bathe a resident, information on dementia, and general unit procedures and practices:

> *The one training that is available that we do for all the staff here at the facility is every staff member that comes to the unit, there is a box that we put together of information about dementia and in that box there'd be the rules for the Health Care Aide, RN, whatever, routines, , and some policies in regards to the unit itself; specific to this unit. There's how to bathe a resident with dementia care, what is dementia?, types of dementia, behaviour mapping, so those are things. (Meredith, Managerial Staff, p. 4)*

This was provided to staff on hire on all behavioural units. The orientation package included a list of videos and training resources they were to review and sign off on upon completion. It was not monitored by managerial staff which meant that actual completion was based on the honour system. The average time for completion of this package was approximately one month. In addition to this, service education programs in this facility are periodically offered by the Clinical Resource Nurses and include subject matter on familiarizing staff on how to approach and care for residents with dementia, how to remain safe in the workplace when dealing with aggressive behaviours, and how to protect themselves in situations where they or the residents may be placed in harm's way. Some of the programs that were previously offered on these topics included: P.I.E.C.E.S, Prevention is 9/10ths of the Law, Non-Violent Crisis Intervention, and Excellence in Dementia Care. These will be discussed in greater detail in a later section. Managerial staff and the Clinical Resource Nurses seemed eager to provide educational opportunities as they become available:

> *I always let them know what's available. We post things on the unit if there's conferences coming or sometimes we do tele-conferences… Those are posted as well. (Susan, Clinical Resource Nurse, p. 6)*

It was important to them that staff be given chances to further their learning. They also encourage direct care staff to attend conferences on dementia as they become available:

> *The Alzheimer's Society has always got some interesting information. They have good speakers at their annual conferences so I would always recommend new staff to consider that. That's always a good resource. (Aaron, Clinical Resource Nurse, p. 6)*

Lastly, nursing staff receive on the job training shifts on the specialized units where they are paired with a more experienced buddy worker who shows them the routines of the units and assists them in becoming more comfortable working on the unit. This is training method is used across all dementia care units within this facility and is thought to be quite useful:

> *I'm very lucky to have a lot of staff here that have been here for many, many years and they've developed some very strong, good, effective techniques on how to manage people with dementia. And, so what they do is they share a lot of that with new staff and you know, they'll go with new staff. They'll buddy with them and say, you know, "Come with me. I'll show you how you know, to relate to this resident and how to gain their cooperation." So,they do a lot of that. They will also do you know, like if they see somebody and they you know, how they managed their situation could have been done in a different way and more effectively, then they'll say, "Next time, you know what? Maybe offer them this instead and you might get a little bit better compliance." (Meredith, Managerial Staff, p. 15-16)*

The purpose of paring new staff with more experienced staff is to allow the new staff to identify different techniques of how to approach the job and to see how their non-practical training or education can be practically used. The number of buddied training shifts given is handled on a person to person basis:

> *I usually start with three or four shifts and then I tend to touch base with them on a daily basis and I see how they progress so if their verbalizingany issues or concerns then I would facilitate more orientation… so it's really individualized. And sort of you know the person that you're buddying them up with, they give you feedback as well. So if they say, you know they're doing great. They're progressing well, I tend to try them on their ownbut obviously working with stronger staff for support. So, I can't give you a specific number but I tend to start with, with four for Nurses and*

> *Health Care Aides and then we sort of go from there… So I've had people go up to you know, six or eight, depending on what their needs are because I don't want to just sort of throw anybody on the unit. (Charlotte, Managerial Staff, p. 6)*

Each manager felt strongly that all staff members need to be given the chance to receive the amount of training necessary based on individual need. If the staff appeared to be struggling, more was given and overall, a basis to assess this fell on the staff member's prior experience:

> *Depends on their classifications. So, if it's a Health Care Aide, they will get, because I have three units, they get at least two shifts on each unit. So they get approximately six training shifts. If it's a nurse, they can get anywhere between two to four weeks of training. (Meredith, Managerial Staff, p. 6)*

> *It depends on their experience and if they work at this facility already and if they've floated up here. So, you know, I like to give two days, two evenings, to get to know the routine really well. If they're brand new to the facility, if they've been up here before and floated here, I'd probably just start them here. Learn as you go. (Casey, Managerial Staff, p. 6)*

The buddy system is intended to get staff comfortable on the unit. Should staff still feel uncomfortable, managerial staff will step in and assess what can be done to make the transition into working on the unit work for the individual:

> *They'll give them those sort of pointers on how to you know, be consistent in the care and ultimately get to that goal of being able to provide the care. So, a lot of that is done informally. If, for some reason, if they're giving these pointers and the person just isn't understanding that, then myself or the CRN on the unit will get involved. (Meredith, Managerial Staff, p. 16)*

Once staff completes these various forms of training, they become responsible for providing care to residents living with dementia at this facility.

What about the family members?

It would be a mistake not to highlight what opportunities are presented to family members who have persons in care at this facility. When a resident with dementia is admitted into the facility, family members also receive opportunities to receive education and training from the facility. This begins with a formal sit down with unit managers and other relevant staff to discuss the admission. Families receive informational brochures on dementia, contact information for the Alzheimer's Society and Alzheimer's Society support group, and an invitation to attend a family support group offered once a month in the facility itself. They are also encouraged to remain actively involved and to contact the managers or Clinical Resource Nurses at any time with questions regarding care of individual residents. In the support group offered by the facility, staff members are present to answer questions and family members are introduced to other people in similar situations. They are given the opportunity to speak freely about certain issues and to brainstorm about what could be done better. Each session also ends with a presentation of an educational topic chosen prior to attendance:

> *The families come and there's like little educational sessions. So we have one about feeding, and then there's one we had on the different types of dementia, and then they ask each other and they sort of support each other 'cause they might be experiencing something with their loved one. (Casey, Managerial Staff, p. 20).*

The selected topics for these support group meetings are chosen based on what issues family members appear to be bringing up most often at the meetings. It is intended to be a safe space that offers support both personally and educationally to families in need.

Perceived Strengths and Gaps of Staff and Family Members in the Current Provision of Dementia Education and Training for Staff Members in Long Term Care

The following section will discuss key themes identified in the responses of the participants of this study regarding the strengths and gaps in the current provision of dementia education and training. It will begin with a chart listing the key themes found in staff and family member's responses. This will be followed by charts that provide a very brief summary of the main points discovered for each key theme. After this, the themes will be addressed. This will begin with a section from the staff member's points of view and follow with family member's points of view. Each section will highlight strengths and gaps discovered amongst the themes from the participants' views.

Strengths and Gaps of Training Themes	
Staff	**Family Members**
1. Availability 2. Content 3. Staffing/Safety 4. Personhood/Dignity	1. Support/Self Learning 2. Staffing 3. Personhood and Engagement

The reason I did not include both the staff and family members under one umbrella and one set of themes for both is that despite some of the overlap in themes mentioned, the two groups responses were quite different in the emphasis of certain aspects of those themes. It was thought that putting them all together would be confusing since the responses of two very different groups with different positions about this issue would be lumped into one, making it hard to keep the responses of staff versus families separated enough. It seemed more logical to keep the responses of staff and families divided because of the differences in responses, rather than force them to fit together in a less concise way. The following sections will be a discussion of these themes beginning with the staff members, followed by the family members.

The Staff Members

The Staff Themes	
Availability	Staff are pleased with efforts to make courses available and with improvements in prioritizing dementia care in education and training. They identify a need to continue growing opportunities to develop more training, improve current training, and make what is offered more available. There are several availability issues for staff: the actual availability of programs focusing on dementia and continuing programs, the costs of programs, the availability to send staff, and the availability of educators, to name a few.
Content	Staff identify P.I.E.C.E.S as being the most helpful program they have been offered to date. They enjoy the content on approaches. Staff also are appreciative of any course that emphasize safety in the content. They feel they could benefit more from dementia being prioritized in courses offered and agree that P.I.E.C.E.S would benefit from creating a Health Care Aide specific course. Health Care Aides also identified a want to learn more about the medication side of care providing.
Staffing/Safety	Staff are pleased with the more recent prioritization of safety needs through the use of more staff on behavioural units. Recently, there has been implementation of a hallway monitor position to manage hallways for potential safety issues. Programs are also being developed to promote staff safety. Unfortunately, staff still identify safety concerns surrounding both their own safety and resident safety in cases where there aren’t enough staff to provide care to more difficult residents or on more hectic days.

The Staff Themes	
Personhood/Dignity	Staff want to provide person centered care to their residents and applauded programs that prioritize giving them more effective tools to provide care to residents with dementia. Unfortunately, staff also expressed frustrations about barriers to providing person centered care in the long term care setting. Most often, time constraints, a lack of staff, undertrained staff, and dealing with more aggressive residents were mentioned as barriers.

Four key themes were identified in the staff member's responses. These key themes were: Availability, Content, Staffing/Safety, and Personhood/Dignity.

Staff Key Theme #1: Availability

The first theme that surfaced in participant's responses was availability. Staff members were pleased with the fact that courses were being made available at all and that the facility appears to be making a great effort to offer staff what does become available. In fact, several staff commended the facility for doing it's best to make education available:

> *They probably provide more than normal, like other places. You know, they allow the Nurses, as we can send them and as it's offered. They will fund to send Nurses to the P.I.E.C.E.S training… and Health Care Aides, and the Excellence in Dementia Care, and you know, I think anything educationally would be supported for sure. (Casey, Managerial Staff, p. 19)*

Education for staff in the facility seemed to be highly regarded and staff appeared to understand the importance of continuing to provide direct care staff with educational opportunities:

> *Nothing is held back from them. You know, often it's… I, I think it's really good but I think you know, that'd I'd never want to see less. (Susan, Clinical Resource Nurse, p. 22)*

Direct care staff in this facility are not limited when it comes to receiving education. In fact, the facility prioritizes a yearly education regime aimed at keeping staff up to date on various topics, not all exclusive to dementia but is important to note nonetheless. It is important because it speaks to the character of the facility and the value it places on keeping staff informed. Even though not all education is dementia-related, education is still being prioritized which is huge. Now, this is not to say staff are not exposed to dementia education, because they are. They appear to be kept informed about what opportunities are available and are highly encouraged to pursue all available options. When asked about availability of dementia education and training options, staff did not hesitate in describing what was available and what was helpful:

> *We have education every year and we learn things like we take Non-Violent Crisis Intervention, we take P.I.E.C.E.S training and that's really helpful. That's for dealing with people with dementia, how to relate to people with dementia, you know, and treating people with respect, and to how to speak with people who can't always communicate. That and a lot of my training has been on the job and stuff like that, my many years of experience, and yeah. But definitely education day every year and P.I.E.C.E.S training has been really good. (Holly, Health Care Aide, p. 3-4)*

Awareness of available education is important and so, it was refreshing to see that staff were informed about their options. Staff were also pleased with the overall improvement in dementia content being prioritized. As one participant mentioned, this was not always the case:

> *In my school studies which seems a lifetime ago [laughs]...I would probably say dementia care would be bare minimum, the very basic. We did one course on the elderly and basically there was probably you know, a chapter on dementia or something but very basics. Certainly the whole idea of specialized approach to care; that was not something that was in our education. (Aaron, Clinical Resource Nurse, p. 5)*

The growing prevalence of dementia within the population and within long term care has sparked a recognition that there is a real need to continue growing educational pieces for staff. An important first step for this is to make the availability of what education is currently out there known amongst staff and go from there. This facility appears to be doing a good job of that by identifying the need for keeping staff educated and by offering what dementia education they can to staff when they can. In the past, dementia did not seem to be as high of a priority for long term care education but waves are being made to make more information available for health care workers and the staff see that:

> *Definitely improved over the years… I mean I've been a nurse for thirty years and thirty years ago you had no education about dementia. You just knew that people had, "senile dementia." Okay, I mean I haven't heard those words in years but I mean, that's what people were all labeled with. (Meredith, Managerial Staff, p. 20-21)*

In fact, at several points of various interviews, staff identified a growing trend of available dementia education and training by reflecting on the minimal amount they recalled being offered before. One staff also applauded the commitment of the provincial government to fund education because it demonstrates prioritizing dementia education and training for staff:

> *There's a trend. The province wanted to bring in, you know? I know there was a lot of talk about what program to look at. P.I.E.C.E.S is only one option. That's what they decided to go with. So, I'm excited that you know, the provincial government wanted to commit. There's certainly a financial commitment there for the education so that's probably what I think is the most positive thing, is just the trend. (Aaron, Clinical Resource Nurse, p. 36-37)*

Availability for staff was not just limited to availability of actual training and educational pieces that currently exist for them to take but also, to the availability for staff to receive as much on the job training as they needed directly on the units. Training for staff in the facility is individualized and based on suiting the needs of the workers on a person to person basis. Managers adjust training accordingly and check in regularly with staff to ensure that they are settling in well and experiencing minimal issues. Managerial staff were very wiling to do what they could to make the transition into dementia care for workers as easy as possible. Whether workers were wanting more education in general or more hands on training on the unit, managers were very supportive and accommodating:

> *The orientation may vary. But again, I always leave it up to the nurse just to, to let them know, "I want you to feel comfortable. If you feel there's an area where you're lacking some experience and you need some more orientation, come see me. I will book that in." It's never, never a problem. (Meredith, Managerial Staff, p. 7)*
>
> *I usually start with three or four shifts and then I, I tend to touch base with them on a daily basis and I see how they progress so if their verbalizing, you know, any issues or concerns then I would facilitate more orientation… So it's really individualized. (Charlotte, Managerial Staff, p. 6)*

Moreover, if staff experienced trouble providing care at any point, they are encouraged to receive more education and training. Often, staff are provided with opportunities to review older training materials, be re-buddied with another senior staff, or to attend any conferences or educational sessions they may or may not find helpful. At no point, are they expected to suffer without assistance from their superiors:

> *Usually if something is going on like that, usually I am made aware of it or they'll come speak with me themselves so then I'll come do re-assessment with them or do a care day with them and then we'll see what's going on and then I'll help; I'll give my opinion on some helpful tips to try or some alternative they can try. And then, we also do follow up with them again and sometimes we'll buddy them with other staff members or just have a discussion. We also have our Clinical Resource Nurses that comes once a month for a question and answer period, and our educational department comes once a month for a question and answer period. Lots of times things like this get brought up at them. (Susan, Clinical Resource Nurse, p. 19)*
>
> *If somebody's first hired and we're noticing that there are some issues, then you know we'll, we'll pull them aside and we'll discuss it. A lot of it is through staff support;supporting each another in an informal way. Sometimes we'll offer some additional training. It might be that we try to get them to the P.I.E.C.E.S training a little bit sooner…There's dignity and care which is not related to Alzheimer's disease*

> *but it might be something that might be helpful for their approach or there's the Excellence in Dementia Care which is you know. So there are sessions out there that you know, we try to get them to attend quicker so that, that might help the issues. (Meredith, Managerial Staff, p. 16-17)*

There is no shortage of support offered to direct care staff within this facility. Mangers and Clinical Resource Nurses are very encouraging and try to accommodate their staff in any way that they can. In cases where direct care staff members express a desire to attend educational sessions, managers work to accommodate them as best as they possibly can:

> *I'm a firm believer of education and the more education you have, the more tools you'll have to use, um, so if any staff member finds something on the WRHA site that is pertinent to the unit, whether it is dementia specific or something else… I'm always very supportive so as long as they're approaching me and letting me know the dates then I try and work with them the best that I can. (Charlotte, Managerial Staff, p. 6)*

Staff members seem pleased with managerial staff members taking their educational concerns into consideration when discussing availability. They feel that managers are approachable and that their concerns are handled in a supportive way:

> *They're very easy to talk to and they're easy to identify problems… They're supportive with whatever you want to do. (Shirley, Health Care Aide, p. 29)*

Staff members are also encouraged to pay attention to the bulletin boards on the units and in the main lobby of the facility. As education and training opportunities are made available, they are posted on the bulletin. If a staff member sees something they wish to attend, they may bring it up to their managers and make arrangements to receive the education.

Overall, staff members had many positive things to say about the advancement of dementia education and training over time. They were also positive about the fact that the facility was doing its best to make what it could available to staff members. That being said, many issues surrounding availability also presented themselves. Primarily, there was a lot of concern about the frequency of education being provided, the barriers that get in the way of receiving education and training, the lack of continuing educational opportunities, and the lack of solid program availability. Each of these issues contributes to lessening the quality of care residents receive and will be discussed in further detail now.

In highlighting the strengths of availability earlier, mention was made to a group of different programs that have been offered within this facility at one point or another. Most of these educational opportunities took place in house but some required attendance outside of the facility. Of the aforementioned training sessions, P.I.E.C.E.S is the only one that is still guaranteed to be provided at some point. The others have slowly become offered less and less for various reasons. One particular problem that was addressed in regards to this, was the fact that there is a lack of regional educators to teach these specific courses. For example, a violence prevention program Prevention is 9/10ths of the Law has not been offered in some because of a lack of qualified educators:

> *That was being offered throughout the region for a while but that's pretty much fallen by the wayside. The last I heard, there's maybe one trainer left in Winnipeg that's qualified to teach Violence [Prevention] is 9/10ths. (Aaron, Clinical Resource Nurse, p. 13)*

Others are not offered frequently because of associated costs:

> *There was another program that used to be around. Non-Violent Crisis Intervention and that was going around for a while but that program you, staff are required to renew every twelve or twenty-four months and there's a cost with every renewal. It's a half-day renewal or something. The original program's like two or three days and then every twenty-four, twelve to twenty-four months, the staff has to go for a renewal and there's a cost for every renewal so it's gonna cost the region huge money to; So that disappeared so there's not much going on in that. (Aaron, Clinical Resource Nurse, p. 14)*

These two programs are not specific to dementia but can be useful for staff members who are dealing with residents who display escalatory behaviours or aggression. In particular, Non-Violent Crisis Intervention equips staff members with the tools to preform safe hold on residents who are putting themselves and others in harm's way when their aggression cannot be easily controlled through re-direction or other methods. This protects both staff and resident's from unnecessary injury and promotes overall safety. Several programs within long term care offered to staff members are not geared specifically towards dementia which makes equipping staff of dementia behavioural units for on the job training even more difficult:

> *Unfortunately there's no here's the class for dementia that you're gonna take, and you're gonna get a certificate in this, unfortunately not, but I think that would be very, very beneficial. (Charlotte, Managerial Staff, p. 9)*

With there being this apparent formal training gap, many facilities must rely on the production of informal training for staff who work with people with dementia. The training is needed but there just doesn't appear to be enough out there. Or perhaps, it is out there but it isn't being made available enough for facilities to utilize. Awareness is a huge factor for availability of resources:

> *It's a lot of informal… training because there's nothing really formal out there. It really kind of lacks some resources. There isn't anything formal. Like, if we find that there's something new and upcoming then we'll certainly look at it. (Meredith, Managerial Staff, p. 12)*

Staff members who work with individuals living with dementia need to receive training that focuses primarily on how what they are meant to be learning is applicable for individuals working with residents with dementia. These residents require specialized interventions and standardized long term care training is not sufficient in some cases when provided to behavioural unit staff members. The fact that most programs mentioned in this study were generalized and not specific to dementia caregiving was moderately concerning. One program, however, that was focused on by all participants because of it's applicability to dementia care was P.I.E.C.E.S. For this reason, it seems appropriate to provide a sub-section on this program being made available to staff.

What is P.I.E.C.E.S?

Up to this point, it should be clear that the availability of dementia specific education and training for staff dealing with residents who have dementia is extremely important. Currently, many programs being offered to staff are not dementia specific which poses problems for staff who work with this population. In talking with participants, it became very clear very quickly that one program stood out in their minds as currently being the most helpful in regards to dementia care. That program is called P.I.E.C.E.S. So what is it?:

> P.I.E.C.ES is a provincial learning strategy targeted to provide a framework for why a person with dementia may behave in a certain way and what resources are available for staff to aide them in providing care to these individuals. P-I-E represent an individual's Physical, Intellectual, and Emotional health, C is the centre-piece or focus in care. This is the maximizing of capabilities of the individual to promote quality of life. E-S represent the environment that an individual interacts with (physical as well as the emotional environment) and the person's social self (cultural, spiritual, "life story") and support network. The P.I.E.C.E.S (Physical, Intellectual, Emotional, Capabilities, Environment, Social) are the cornerstones of the philosophy and care of the P.I.E.C.E.S. approach. (Retrieved from: http://pieceslearning.com, 2016)

P.I.E.C.E.S was originally designed for nurses alone and was meant to be a train the trainer model. In a train the trainer model, the individuals who participate in the education are supposed to relay the knowledge and skills they learn to other staff members. In the case of P.I.E.C.E.S, the intention was to have the registered staff be educated and then have them train the Health Care Aides informally. It was set up this way due to a shortage of funds but somewhere along the way, the original intention of the model seems to have been lost in translation as many of the staff in this study felt that the Aides required more formalized training. This will be discussed further in subsequent sections.

In the early stages of the interviews, participants were asked to talk a little about what education and training they were currently being offered or what they have taken in the course of their employment and the time leading up to their employment. Staff unified in discussing the P.I.E.C.E.S program as being the most useful option currently being made available to them since it focused exclusively on dealing with individuals who display more difficult behaviours and who suffer from various mental deficits. I have chosen to include this program information in this section of the document and not in the background information for a few reasons. Prior to conducting this study, I was not aware that such a program existed and after speaking with some co-workers and friends in health care, I came to realize that its availability is not common knowledge to everyone in the health care field. In my literature review, I discuss this problem of regional variation and non-uniform training from facility to facility. Because of this, I felt that discovering this type of program was available at all, was a finding of its own and needed to be placed in the findings section on availability, not in the background information.

The P.I.E.C.E.S program was developed for Nurses and professionals in the health care field in an attempt to alleviate some of the frustrations staff experience when working with this population. Formally, P.I.E.C.E.S is a four day training session developed for Nurses to attend. There is no formal P.I.E.C.E.S education for Health Care Aides but this facility has made educating Health Care Aides a priority and developed it's own one day session of P.I.E.C.E.S that incorporates some of the modules from the P.I.E.C.E.S for Nurses in an attempt to help educate these workers as well. This is a huge strength in the availability of education offered by this facility exclusively. Prior to investigating this topic for my thesis, I was unaware that such a program existed which could be considered a finding of it's own. When I asked around the facility in Ontario that I work in, very few of my co-workers knew what I was talking about. In the literature review, I mention the gap about how education may vary from region to region and within facilities. This is a perfect example of that. Here, you have a program that appears to be quite useful that is being offered only within some facilities and only to some workers. Staff in this study commented on how they knew other workers in other facilities who did not get P.I.E.C.E.S training. This is important because it draws attention to the need to address these service gaps in education and also, to prioritize a more unified and wide offering of programs.

Participants in the study all had positive things to say about P.I.E.C.E.S in regards to content. This will be discussed in subsequent sections. In terms of availability, they were less positive in discussing the program. They were grateful for its existence, but were not happy with the extent of its availability. Like many other forms of education, it is not offered on a frequent enough basis and is not made available for all staff to take:

> *The unfortunate thing with P.I.E.C.E.S though is that there are only so many courses offered throughout the year and they tend to fill up very quickly so typically there's waiting lists or you… it's very difficult to sort of work in, so there might be a lot of interest. I've had staff members, they want to go, but then the dates don't work or they can't get in, so that's the other downfall. (Charlotte, Managerial Staff, p. 5)*

It doesn't help that the actual long term care facilities themselves are placed on waiting lists by the WRHA for when they are eligible to take part in training sessions. This makes it difficult for managerial staff to arrange training for staff members and places workers in a difficult position where they must work with this population while being held back from information that could make their jobs a lot easier. Some education exists and yet, accessibility issues and limited availability makes actually attending a P.I.E.C.E.S program very difficult. Within this facility, some Nurses have received P.I.E.C.E.S training but the remainder must now wait until it is the facility's turn before they too, can complete it:

> *Right now, the way that the training is working is there, they've grouped the personal care homes into groups and so let's say, for 2015 they're focusing on six or seven nursing homes to get all of those nursing homes done and then they're gonna go to the next group of nursing homes. So although we've done a lot of training with the nurses, they decided to go to this kind of training a year or two ago and our group hasn't come up so I haven't done any P.I.E.C.E.S training for the nurses to this point and I'm waiting. It's not for me. I don't make the sessions. It's up to the WRHA to let us know when it's our turn. (Meredith, Managerial Staff, p. 9).*

Several participants felt that there is not enough being offered in the province and that the registration process and waiting lists hinder the progress of having fully educated staff within a facility. Many programs have limited availability, meaning only so many staff members can attend at any given time. Where this is the case, issues can arise with the consistency of care for residents as some staff have received education and others have not:

> *You can't have two Nurses out of ten educated and expect to be doing a good P.I.E.C.E.S program. So, if we're told we're allowed to send six Nurses per year from*

> *this facility for education and we have two hundred Nurses and our turnover rate is about thirty a year, are we ever gonna have enough staff to really do a P.I.E.C.E.S program? So, definitely we need to have more availability for staff. (Aaron, Clinical Resource Nurse, p. 34)*
>
> *All my Heath Care Aides have it because it's a day and there's plenty of them to backfill for staffing to send them but the Nurses, I'd say, like, I'd say half of them might have it. (Casey, Managerial Staff, p. 6)*
>
> *They do it when we have an opening to get it done. So, do I have Nurses right now that have no P.I.E.C.E.S training? Yes I do. I have several. (Meredith, Managerial Staff, p. 9)*

Some participants were frustrated by this but felt that there was little they could do besides wait for it to be made available to them. They are forced to make due with what resources they have. This includes looking for other educational opportunities as they become available and by utilizing the knowledge of all the professionals involved in the resident's care:

> *I always send them updates with you know, dates that are approaching or upcoming… teaching stuff but, like really again, then the issues is, is the availability and then the classes are limited to so many participants and so, yeah no, unfortunately we sort of have to work with what we have…You kind of feel stuck because you wish that you could offer more to the staff, you want everybody to have a certain comfort level, but then depending on the escalation and the issues that kind of transpire, you can't always prepare people. (Charlotte, Managerial Staff, p. 14-15)*

There is also the issue of making staff available to actually participate in the education that is being offered. When you remove a staff member from the floor, that's a staff member that needs replacement. In long term care, you cannot remove staff without replacement because resident care care is a 24/7 job. So there is that constant battle between actually having the information and education sessions out there as well as how to realistically have all the staff attend. Specifically, managers feel frustrated about this because they want to provide their staff with educational opportunities but face barriers to doing so. One commented:

> *It's very difficult to get people into education because when you take a person to education that's a staff member that can't work so you're always fighting those odds, right? If we could take the whole group off the unit and educate them and then put them back on the unit and could get somebody to watch the unit while we're doing it… That would go a long way but I know I'm being, I know that's unrealistic… So, could there be a better job in, in education? Absolutely, without a doubt. There's just not enough resources out there for it…The information has to be out there. Who's going to create sessions, right? You want the education there but who's going to do it? ... Then we need people to attend, and then we need the people to relieve them. So you're fighting that all the time which makes it, makes it difficult. (Meredith, Managerial Staff, p. 19-20)*

There are also limitations on the frequency that continuing education is offered. Taking part in one educational course or training session on dementia will be beneficial for workers but will it really be enough to sustain someone working in a career for thirty plus years if they take these courses at the very beginning? It is safe to assume that with time, some things fade and people may need to be refreshed on certain topics. They also need to be made aware of any advancements in techniques being developed to make providing care easier and advancements in treating the disease as well. Different forms of dementia will require specialized forms of approach and training that staff need to be educated on and familiar with over time. Participants appear to feel the same way about continuing education:

> *I think it's always good to review because there may have been something they've forgotten to realize or it might help them acknowledge something that they didn't realize they were doing or not doing, so I mean I think that they always need training. (Susan, Clinical Resource Nurse, p. 22)*

Frontline staff were especially interested in having follow up training:

> *There's nothing that's just like P.I.E.C.E.S. There's nothing that's every year, "Let's freshen up." Everybody needs a refresher to look back and just say, "Oh maybe I'm not doing that so good anymore. Maybe I need to…" I don't know. I think it would be good. (Melissa, Health Care Aide, p. 26)*

> *You forget, like even, because I mean we took it before. Actually this facility offered it I think in the late eighties also. But, you know, you go on through life and you just forget. You just, you know you don't, you don't remember. (Shirley, Health Care Aide, p. 30)*

Managers had similar feelings and thought that refreshers could help workers keep up to date on what is new in dementia care as well as to just keep them remembering all the techniques they learn in training to provide care:

> *Even caravanning around the staff and coming up and showing like, five/ten minute presentations: "This is what's new in dementia care. This is how… Is a person being aggressive and you don't know why? Remember to check this, this, and this." Like, just little updates. (Casey, Managerial Staff, p. 22-23)*

One Health Care Aide had taken the P.I.E.C.E.S course for a second time and commented on how things had changed, suggesting that it is important to continually keep frontline staff providing direct care updated. She felt that it was a much needed refresher that helped her reorient herself in the job site and enabled her to provide higher quality care again:

> *I can't remember the first time I went to P.I.E.C.E.S and then just recently, in this April was when I was scheduled to go and a lot was changed and a lot was different. Some of it was the same but, But it changed. (Shirley, Health Care Aide, p. 31)*

One final availability issue was the lack of dementia specific education for Health Care Aides. As mentioned at the beginning of this section, P.I.E.C.E.S was originally developed for Nurses, not Health Care Aides and so what this facility did, was develop a one day P.I.E.C.E.S training for Health Care Aides on its own. Mirroring P.I.E.C.E.S for Nurses, the Clinical Resource Nurses adapted a couple of the modules that were relevant to Health Care Aides and began to teach them to groups of Aides working on the behavioural units on their own. They've also made a point to try an educate them swiftly where applicable:

> *One of my big concerns as a Clinical Resource Nurse was the lack of education for our Health Care Aides because our Nurses were going to this four day P.I.E.C.E.S, Health Care Aides were getting nothing and there was nothing really much available for Health Care Aides. And so I went to a meeting at the Alzheimer's Society as I said, on a couple occasions, as I said, voicing that really our Health Care Aides and unit assistance need to have, need to receive education about approach because they're the ones who are doing most of the care… So we investigated whether I would be able to use the, the P.I.E.C.E.S modules to create some education for the Health Care Aides at this facility and we were told, " Yeah absolutely as long as the ones presenting it had gone to the four day P.I.E.C.E.S workshop." They would be deemed qualified to you know, present these modules so, so that's what we've been doing. We utilize I think it's three of those modules. I think there's eight available and we chose three to review. (Aaron, Clinical Resource Nurse, p. 15-17)*

This is a move in the right direction but Health Care Aides need to have their own specialized, formal, and provincially regulated and approved training since the majority of this course is geared towards someone with a Nursing background and Health Care Aides do not receive the full extent of training from P.I.E.C.E.S that they could:

> *They don't get to do the four day P.I.E.C.E.S training. A lot of it is probably too in depth because you're already expected to have your Nursing degree when you go to it. But I think, some smaller, more educational packages to be available and actually I've kind of started on working on doing that. I've just made a new duo tang with some helpful hints and dos and don't and we're just starting to talk about those in our shift reports. (Susan, Clinical Resource Nurse, p. 8-9)*

More educational packages would indeed be helpful but it should not be looked to for the long term solution from region to region unless said smaller informational sessions and packages will be made mandatory and standardized across facilities. Furthermore, since P.I.E.C.E.S currently appears to be the most noted program amongst staff, a good first step would be to develop it further for all staff and make it formally available for Health Care Aides. The staff in this study seemed to agree:

> *I think that they should have a P.I.E.C.E.S specifically made for Health Care Aides you know, because they, even though we can educate them, we do it, it's not quite as*

> *in depth as… the medical background on to why these people are acting how they're acting and that it's not their fault to say, you know they're not being bad or misbehaving they're just. This is their reality right now and sometimes I find it to be…I often think it would be useful if these Health Care Aides had an actual training day, specific for them to learn about these types of things and then to go over how to deal with them.(Susan, Clinical Resource Nurse, p. 15)*

Furthermore, if P.I.E.C.E.S is the program chosen to be implemented, it should be unified from region to region so that all facilities can get on board with one another and be on the same page for staff and resident well being. It is concerning that education for staff members who provide the direct personal care to residents living with dementia does not appear to be as highly prioritized as it should be. This particular facility is exceptional in that it has made a point to create its own opportunities for staff but even the participants have identified a need for a more formal option to be provided to the Aides and for more facilities to be unified in what dementia education training is required for staff to have.

Staff Key Theme #2: Content

After some initial conversation about what dementia education and training was being made available and a discussion on some of the strengths and gaps with availability, staff began to talk about the specific courses or programs they took in more detail. Across the board, P.I.E.C.E.S training was mentioned most frequently when talking about content that was most enjoyable and helpful to staff who provide care. Staff members and particularity, Health Care Aides, found it very helpful to actually be receiving dementia specific training material:

> *I think it should be mandatory to be taught. It's… for special care dementia. If you're taking a Health Care Aide course, I think the Health Care Aide students should have it because when I took the Health Care Aide course it was through the community college and like I said, it's very broad. It just covers personal care. (Shirley, Health Care Aide, p. 6)*

The course was described as being very comprehensive and participants were pleased with the tools it equipped them with to preform care more realistically. It emphasized the classifications of dementia and how to approach care in a variety of ways. For Nurses, there is also some discussion about medications and caring for individuals with dementia. All in all, staff seemed to appreciate the overall content

> *I think the P.I.E.C.E.S training was a very good training course. I think it's very comprehensive. I think it's a good basis for anybody that's newly entering dementia. They offer a lot of good tools. (Meredith, Managerial Staff, p. 16)*

Overall, the program content was spoken highly of:

> *I think the whole thing really helped with the different tools that were out there but it just kind of put everything together so I found the whole thing helpful. There's not one piece I found more helpful… I thought it was really good. They go through the different kinds of dementia. They go through what you might see with what and why and that when people start becoming aggressive usually it's for a reason. They might be constipated. They might be hungry. They might be, who knows-in pain… It was a really good course. (Casey, Managerial Staff, p. 12-13)*

Content of this program focused on having staff understand how to provide more holistic care and to do so in a way that benefits all parties and that provides a care plan to suit individual resident needs:

> *A lot of what the P.I.E.C.E.S education is about, is about doing an assessment, a holistic assessment and doing all the different tools that they use in order to complete a thorough assessment. So that's… that's what I got most out of P.I.E.C.E.S, is having that framework and that tool that interdisciplinary teams can go by to… it kind of insures that you are doing that thorough, holistic assessment. (Aaron, Clinical Resource Nurse, p. 8)*

The P.I.E.C.E.S course for Nurses contains a series of modules that cover a variety of topics on dementia. These include a description of the different types of dementia, different techniques staff can use to approach individuals to provide successful care, and a synopsis of some of the medication classification and drug interactions, to name a few. Participants continually mention being given the, "tools" to care for residents. What they are referring to, is a set of skills being taught in the course that aides them in being able to preform resident care. The tools being referred to include some of the pointers the program gives staff to obtain more compliance in providing care or providing medications; really any situation where a staff member's goal is to gain compliance and provide care:

> *They show you different ways to live in the moment with people with dementia, different ways you can respond to things; when it's appropriate to have to use your re-direction, when it's appropriate to start using your PRN medication, how to speak with these people., It really helps with the communications. It gives you lots of different tips. You know, cause every individual with dementia is an individual. Nobody is the same with how they're going to be affected, what responses they're gonna have, or what behaviours they're going to develop and it helps to learn to be able to identify what is happening in the moment. (Susan, Clinical Resource Nurse, p 12-13)*

It was mentioned previously in this document that dementia is an umbrella term and that several forms of dementia exist. In my experience, both as an Aide and in conducting this study, I have come across the finding that many people working in the long term care setting are unaware of this fact. Many people still use Alzheimer's as the go to term for someone who lives on a dementia care unit. This is unfortunate because not all dementias are the same and to categorize them as such, will have major implications on care provision. Educating staff on the different types of dementia is beneficial because it distinguishes the various behaviours that are more common in one than another and give staff a basis to work from for approach, etc. Someone with vascular dementia will require modified care approaches to someone with Lewy Bodies. In the P.I.E.C.E.S adapted for Health Care Aides, staff really appreciated having information that allowed them to distinguish between the types of dementia:

> *What I found interesting too is how there's different forms of dementia. Like there's stroke, Lewy Bodies, you know, frontal lobe, like all the different forms of dementia. So that was interesting in how it affects the brain differently like some people are non-verbal, some people you know, are, yeah. Or, early onset Alzheimer's and things like that. It was interesting. (Holly, Health Care Aide, p. 9-10)*

Giving staff this information enabled them to better understand individual residents and what is happening in their minds. It equipped them with the understanding that care needs to be personalized and that all individuals are individuals who may require specialized approaches for their care:

> *There's so many different variations of dementia. There's variations of Alzheimer's, yeah. Someone who has Lewy Bodies, they're the ones that typically have the delusional and… the one's that will strike out and then there's some that will just have the Alzheimer's where they don't remember you. They don't remember them. They don't remember themselves. Yeah in identifying which like Frontal or Lewy Body you know? Instead of just bridging it like Alzheimer's. Now you're finding that there's actual parts of the brain that are affected so they know that the dementia is going to react that way. It's their memory… of course they're not gonna have that if it's their motor functions well then they're gonna lose their ability to walk and then there's the speech. (Shirley, Health Care Aide, p. 13-14)*

In these responses, one can see that they staff began to identify better with the residents and appreciated their need to be understanding of certain behaviours and to be more flexible in the care that they provide. They were also pleased about how understanding about the different types of dementia in more detail, paired with learning more ways that they can approach more aggressive residents would assist them in providing better care:

> *I pretty much learned just, as I went and just saw different people's techniques of what worked better, what, and just my other years of caring; and I had experience, like I said but not, not so much with the aggression that sometimes goes with caring for people with dementia… Then, as I was on the unit more, then I went to a P.I.E.C.E.S workshop which I found was really great in helping you understand the disease better. Just the different thing-just the different levels; even the different kinds of dementia 'cause we didn't really know that there was different behaviours that*

> *went with different kinds of dementia so that was helpful. (Melissa, Health Care Aide, p. 3-4)*

> *It gives you a good idea of what the person that you're caring for, may be experiencing so that you're kind of able to adjust to dealing with that patient according to what you know and how you interact with them. (Shirley, Health Care Aide, p. 5-6)*

The Health Care Aides appreciated being given tools to communicate more effectively with their residents. They appreciated that the content of the P.I.E.C.E.S program adapted for them focused on how every individual is an individual and every behaviour has meaning. The program focuses on the resident as a person and reminds staff to take that into consideration when providing care. One participant commented on how being introduced to better communication skills has helped her in the work setting:

> *I think all the communication skills we learnt working with people and all the different signs, that was really important. Like, if someone's really upset sometimes they'll, "Oh that person's just upset," but we're learning through this like, someone could be in pain, someone could have to go to the bathroom, like, little things like that and you learn to think more. Like, "Aha," maybe this person is this way because of certain things you know so. It makes you think… Sometimes our days are so busy but I see people taking time to talk with people and you know, and hold their hand. Touch is really important too and I learnt that in P.I.E.C.E.S too. That's really important.To talk to someone and hold their hand, you know. Or give them a nice… you know, rub their arm or something like… Sometimes touch is so good, you know? And things like that. Yeah and your tone of voice and I see that. I see people talk to people and people are human beings 'cause all the people I work with are wonderful human beings with… some of these people have incredible lives. They've raised children and yeah and like my co-workers, most of my co-workers, they treat the resident with the utmost respect and love, and devotion, you know, it's great. (Holly, Health Care Aide, p. 31-33)*

Two Aides made reference to a couple of videos on dementia care that they found especially enjoyable because they stressed that personalized care approach and framework for delivering more compassionate care. The videos also served as a reminder to remain patient with individuals who may not be able to communicate. One staff reflected on a video that stressed personhood and how some residents memory brings them to a place where they are experiencing their life differently:

> *We saw a really good video in P.I.E.C.E.S training about the lady in the red dress. I don't know if you've ever seen it; and that was interesting. How she sees herself different than what people see her as 'cause a lot of our residents, their long term memory, some of it is intact and their short term memory isn't as good. (Holly, Health Care Aide, p. 4)*

The lady in the red dress is a woman living with dementia who sees herself in the mirror as a younger version of herself who doesn't realize she has aged with this illness. It stresses that staff need to be adaptable to living in the moment with residents and to appreciate that individuals may not identify with the same reality as staff. The Aides also appreciated the introduction to music therapy and learning about how people living with dementia can become enlivened by the sound of a familiar song. These elements in the training provided staff with tools to communicate with residents more effectively:

> *There was a couple of videos that really struck your heart because it showed; one was an elderly lady that didn't really speak but then there was this woman who would sing to her and she just came alive. It just showed that, you know sometimes we look at the elder and if-because they aren't communicating, we maybe forget that there's somebody in there that's alive, that can come alive if you do music or different forms of communicating with them, not necessarily speech. That was sort of… I mean we see, I've seen that too on our unit but yeah, it just. It was a very heartwarming video. And, I think just different ways of communicating that, and being. Learning just to be patient. (Melissa , Health Care Aide, p. 7)*

P.I.E.C.E.S for Nurses also describes ways to make individual care plans more successful through assessment. Resident assessments are important for all residents but especially important for residents with dementia because they allow for more individualized care planning. From one

Clinical Resource Nurse's perspective, the contents of P.I.E.C.E.S was useful because it laid out a very well organized framework for assessment of residents:

> *What I found very helpful was the framework for assessment. Like that, that kind of really brings a lot of information together and gives you a solid framework to go by. That I found helpful. That was sort of, the most concrete assessment plan I had come across in a long time. (Aaron, Clinical Resource Nurse, p. 7)*

This framework for assessment also pushes for more interdisciplinary teamwork to provide higher care quality to residents. This means that in order to provide a more concrete and holistic assessment, Nurses, Social Workers, other professionals, and families need to work together. Staff seemed to appreciate this because it allowed them to have different perspectives working together to provide the best care plan possible. Furthermore, the involvement of families enables these assessments to provide not only a resident centered care approach, but a resident-family centered care approach. But interestingly enough, despite being given this training, many staff still found that their hands on experience contributed to a larger understanding of working with these individuals. This could be due to the fact that dementia education and training has only recently become more prioritized and the staff in this study who received P.I.E.C.E.S training had already been working in the field for some time. This being the case, staff in their facility really had no choice but to learn on the job over time. Regardless, staff still found the content of P.I.E.C.E.S to be most helpful in refreshing them on some things and praise it for being the best they've received thus far:

> *I think that P.I.E.C.E.S is probably the strongest eduction that they could provide that I've been to and I'm sure there's certainly more stuff. We could go to the library and read about, learn about, but, for me, I'm an on the job… I like to learn as I go on the job. I find that just working and seeing other people and how they do certain things and getting tips from them has been the most benefit for me. (Melissa, Health Care Aide, p. 29)*

Most participants in this study had been employed in dementia care for some time and so, working with dementia was not something that was new to them. They had slowly developed a series of skills on their own before being provided education. One participant commented about whether or not she'd learn best from being educated prior to being placed on a unit with residents living with dementia or by learning on the job:

> *I think it's 50/50 like, personally, like, I learn best in those situations but, if you had some form of a base, to sort of go by, I think that, that would just help the situation in the end so I think.. yes… You can't teach every situation and you can't give you know, this is what you do for this, and here's the algorithm and it's that simple. Like, it's never that simple because everyone is so different, right? But, I think if you had a good basis or a good couple of tools to use or fall back on or this is what you do like, I think then that, that would help… maybe the comfort levels and then maybe de-escalating certain situations or preventing some situations, for sure. So, I think that they kind of go hand-in-hand. (Charlotte, Managerial Staff, p. 15-16)*

Some things need to be learnt hands on in care provision but not everything needs to be. By equipping staff members with tools to provide care, prior to entry into the workspace, employers will be ensuring a safer work environment for both the staff and the residents. The issue of safety will be discussed in subsequent sections. Overall, staff were pleased with the content of the courses they've received and P.I.E.C.E.S was identified as the most dementia content rich of any they had received thus far.

Staff seem generally pleased about the content and framework of the P.I.E.C.E.S program and were mostly positive when questioned about its overall content. There were a few suggestions for what could be added or explored further in regards to the content of other education and training as well as P.I.E.C.E.S that will be addressed here. Broadly speaking, staff were less pleased about the amount of content they were being taught before being hired at all.

They also expressed a desire to receive more training in both injury prevention and end of life care for residents with dementia.

Education and training on dementia specific content is not focused on nearly enough in the early stages of learning for people who intend to work in the health care field. Participants found that at the core of their earliest education, dementia was not prioritized. This was the common finding among both the Nurses and Health Care Aides. For Nurses, one Clinical Resource Nurse recalled only being taught a basic mental health course in University that covered a vary broad range of mental health topics, with dementia content being very minimal. The same issue came up for all three Health Care Aides in this study. In their earliest form of education, the Health Care Aide course, not one could recall much, if any, content on providing care specific to individuals with dementia. One commented:

> *They just basically, they focused on personal care, which is general. Like, you know, bathing and feeding and not… pretty main stream. Not in, not in getting into the special care unit like P.I.E.C.E.S stuff. (Shirley, Health Care Aide, p. 5)*

With this being the case, Aides working on the dementia care units were forced to learn on the job when they were hired and receive training much later in their careers that had content specific to dementia. This suggests two things: The first, is that dementia was not prioritized because it was not considered necessary or recognized as being as important as other subject matter in these courses. Secondly, the increase of prevalence in dementia in the population has only recently been acknowledged to the point where content on dementia is being more widely offered. The lack of dementia specific content in beginning eduction may be partially due to the fact that not every Nurse or Health Care Aide may end up working in long term care or in behavioural units for people with dementia. Although this may be the case, by disregarding a disease that is very prevalent in the population, one is setting up future workers for failure or at the very least, a more difficult time in the workplace when they come into contact with these individuals. The majority of participants of this study had no solid framework to build off on before they were placed into work situations that dealt with providing care to individuals with dementia. For the most part, their training was on the job and they needed to learn as they went or to learn from others. People are not always sure about how to approach theses residents or how to communicate. This can be a real source of frustration for the residents and the staff already working on the units. One staff described first working on a behavioural unit as a real eye opener for some.:

> *A lot of people when they come into this job, they don't realize…like a lot of people will take things personally. They don't realize that some people with dementia, they have aggression, different personality changes; so that's kind of a big eye opener. When you're seeing this at first you're like, "Oh my goodness. Someone's hitting me or someone's swearing at me," but then after a while, you know... They should warn people about that. Not to take it personally and this is the disease and not the person. So I think that would have been more helpful because it's kind of a pretty big eye opener... People who take the Health Care Aide course should learn more about that. Definitely. And, also how to deal with people and not to… I'm trying to think of the word when you treat someone like a child or baby and also, learning how to speak to people who have dementia. Like, not like, "Oooh," 'cause I know sometimes people treat like individuals who have dementia, they talk to them like they're a child and they're not a child. Or, even using the word diaper, like. We don't use that word that's- or bib. It's like, no. That's a clothing protector. So a lot about communication and all about personality changes that person goes through, yeah. I think it's important, yeah. (Holly, Health Care Aide, p. 5-7)*

Staff on these units are also expected to adapt quickly in a very short time frame:

> *I think I probably, maybe had like two or three where I was shadowing with another co-worker to sort of, get used to the unit and then you're on your own [laughs], no. Then you're supposed to dive in and yeah, like I said, it, to me, it's, it's a lot of learning as you go and figuring out you know, "Okay that didn't work so I'm going to try a different approach," and then you get to know the residents too; what works*

> *for them, what doesn't, and, and then you have to work with your co-worker too you know. (Melissa, Health Care Aide, p. 10-11)*

This process of learning on the job becomes more difficult when staff have no prior education or experience working with people who have dementia. Shadowing fellow coworkers is helpful but by doing so, one begins to rely on that co-worker's knowledge. Have they had dementia specific training? Do they understand that there are differences between the dementias? Are they well versed in approach? These are important questions to ask because if facilities are going to rely on other workers to provide the education to new staff, they need to be sure that the training being given is appropriate and sufficient. It doesn't seem appropriate to have new staff being taught by someone who does not have a basic knowledge about dementia themselves. One staff member shared her experience with discomfort when first working on a behavioural unit:

> *It was more that their, the physical outbursts. In just a nanosecond they could go ballistic. That I wasn't prepared for or not use to. I mean, in rehab, yeah they get mad and bang their cane or pull on you or whatever but the special care unit they'll actually physical punch you, physically scratch you. You're eyes, they'd scratch your eyes out, pull your hair out so, yeah. If you're caught off guard, there's harm to you and harm for them. (Shirley, Health Care Aide, p. 10)*

From this account, it is clear that preparation is a key aspect to the success of workers who are providing care to residents with dementia. It is unacceptable to think it is okay to throw someone into a potentially violent environment without at least briefing them about what can be expected before they enter the environment, not after. So yes, most agreed that they learnt as they went and that having education later was helpful but there surely must be a better solution for workers than being thrown into situations where they do not know what to expect. Prior education about what can or cannot happen with residents living with dementia is essential for staff and resident well being. In fact, many participants expressed concerns over the lack of content on safety being given:

> *The other thing that, there's a real need for is, is, injury prevention and what I mean by that is defensive techniques for staff. Ways to prevent being injured as an employee. There's a real lack there. (Aaron, Clinical Resource Nurse, p. 11)*

There are programs aimed at injury prevention out there but as mentioned in previous sections, there is a lack of availability of these programs and staff really want to learn more about how to protect themselves and residents in situations where behaviours may escalate. In particular, two staff felt that Non-Violent Crisis Intervention needed to be offered more frequently because they found it extremely helpful from a safety perspective. One commented:

> *Sometimes I'd wish we'd learn a little bit more about Non-Violence Crisis intervention, a little bit more. You know, 'cause and everyone be on the same page about that 'cause you're working with different people and sometimes you're going to do care on a person that's aggressive, they might not know how to hold properly, or safely you know? So it's safe for the residents and staff and things like that. That would be good to know a little bit more about. (Holly, Health Care Aide, p. 12)*

Content of dementia education and programs must explore the safety aspect and take into account how current content can be adapted for workers in dementia care. Another staff commented on the same program and emphasized its relevance to dementia care:

> *They haven't had Crisis Intervention for I don't know how long it's been. That's something that needs to be done because there's so many people who forget and especially with our population of people who physical are, you know, have physical outbursts, so you have to have, find a way to restrain them without harming yourself and without harming them. (Shirley, Health Care Aide, p. 33)*

Managers and Clinical Resource Nurses want to see this course content more too. In fact, a major criticism one participant had about P.I.E.C.E.S was that it did not incorporate enough on injury prevention techniques for staff:

> *If there was one criticism I have for P.I.E.C.E.S, I really came away, not only from the four day education but also from some meetings, a couple of meetings from the Alzheimer's Society where they asked people from different facilities to come together and discuss education needs… When I talked about staff safety, that isn't something that they wanted to… There… whenever you talk about residents being aggressive or causing injury to staff, they very quickly revert to, "How do we avoid residents being aggressive? How can we, how do we deal with this reactive behaviour?" So, before it happens so you don't have to deal with injury prevention. They're all about prevention, which is great. That's great but I very bluntly said to them, "Look. The reality is staff are working on dementia care units and behavioural units particularly, residents can become quite agitated and aggressive very suddenly and without warning and although absolutely I'm very supportive of teaching staff all of the different ways of trying to avoid a situation like that, the reality is, the situations are happening." You know, staff are being bitten, staff are being kicked, staff are being punched, they're getting their hair pulled and P.I.E.C.E.S is all about, you know, resident… caring for the resident and avoiding that and they won't talk about this piece so that's another educational need that we're still struggling with. (Aaron, Clinical Resource Nurse, p. 11-12)*

Thus, some subject matter reflecting more injury prevention techniques could benefit both staff and residents tremendously.

Continuing with some content critiques of P.I.E.C.E.S program, although staff did appreciate the program as a whole, they felt that some parts of it could be modified to better suit their needs as frontline staff. Particularly, while the assessment tool provided was considered to be quite good, some felt it was too long and laborious, preventing staff from being able to have full P.I.E.C.E.S assessments on all of their residents:

> *We have done it on a couple of the high needs residents but it is pretty labour intensive but… you know, I guess if you just know the concepts, I think that could be made easier… I think they need to have a shorter tool… It's kind of complex. It's not like, "Oh, he has pneumonia, give him antibiotics." It's like, "Oh they have a behaviour and they have this and that and this is how THEIR dementia is progressing therefore, this is what they need." And, everyone's dementia progresses differently so we might see this behaviour in this person and that behaviour in this person… I really enjoyed it but the tool, like to sit down with a team and do a whole assessment like… I think we can shorten that somehow. Maybe, like just look at*

> *shortening the tool so we can use it! because I only have it on two or three of my residents 'cause it's so labour intensive. (Casey, Managerial Staff, p. 11-14)*

Assessment is critical to good care planning and therefore, overall care quality. For this reason, it is considered a very important content piece for educating workers. A major benefit of assessment is being able to track individuals' progress on certain medications and to identify when and where medications are necessary to help manage behaviours. The WHRA has made a point to emphasize holistic assessments before choosing to medicate and there are various steps that must followed before medications are used in this population. One staff commented on the importance of having a good assessment tool in this regard and applauded P.I.E.C.E.S for having content specifically on those assessment tools:

> *You want to make sure you're doing that assessment. We deal with a lot of mediations for behaviour like antipsychotics, antidepressants, anti-anxieties, and so on and so there's a lot of chemical and restraint issues around that. There's a lot of new movement in that area of really being accountable for the medication and the reason I defer off into that, into that realm is because when you're… explaining why a person is requiring chemical restraint again you have to do, they really… the Winnipeg Regional Health Authority has come up with a lot of forms. They really force you again, to do thorough, holistic assessment of the situation before you know, considering antipsychotics or other chemical restraints. What other possible interventions can take place? P.I.E.C.E.S fits into all kind of, current trends about wanting to do that holistic assessment. (Aaron, Clinical Resource Nurse, p. 9)*

If the tool itself were shortened or staff were given more training on effective ways to complete it in a less laborious way, they may find it more useful in the long run. By doing this, more residents may be able to be assessed and staff will be able to provide better care plans and preform better care. As a staff member mentioned previously, very few residents have a complete P. I.E.C.E.S assessment. Just as having only a few staff with P.I.E.C.E.S training is not very effective, only having assessments done one a few residents is not going to be an effective approach to care. There needs to be consistency in how care plans for every resident are developed and followed.Staff also felt that the P.I.E.C.E.S program could benefit from focusing more of its content on aggression and how to deal with residents who become aggressive or who display more escalatory behaviours. In particular, one staff member felt that this program focused more on mild forms of dementia and failed to sufficiently address approaches and techniques for those in the more advanced stages of dementia:

> *Sometimes when it gets to severe to end stage, that's when your most challenging behaviours can occur but then when it gets to end stage, that's when they kind of taper off again. So, I think that the P.I.E.C.E.S training doesn't focus in on those really severe, challenging behaviours. Or, feel that there's a magic answer for them [the residents]… I think that's what P.I.E.C.E.S training is trying to tell you, is that, "If you do this, this is what's going to happen." And, that's not always the case because we are working with individuals that their disease is different day by day, person to person. So, you know, what works today may not necessarily work tomorrow. And although they tell you that in P.I.E.C.E.S training, I don't think they hit home on that message enough and they have to really look at those challenging behaviours and go, "Okay, you know, you can try all this but at the end of the day, there may not be a magic answer…" What they say is, "Try all this, it's gonna work out in the end," and I don't think that, that's really, realistic. (Meredith, Managerial Staff, p. 21-23)*

Individuality of the resident should be stressed and staff should be informed about how to best be equipped to deal with the more severe cases, and understand when to approach and when not to approach. P.I.E.C.E.S content is also very Nursing specific and would benefit from having a formal program developed for Health Care Aides. Despite the facility's good intentions to provide staff with education and as mentioned in the previous section on availability, many staff feel that this would be an appropriate next step as they are the workers providing the direct personal care. A lot of the current P.I.E.C.E.S framework is too in depth for what is required of Health Care Aides and the material on assessment is more geared towards Nurses. That being said, Aides would still benefit from being educated more about the medical background on dementia and some of the other content present in the current formal program.

Staff also want to be educated on end of life care specific for residents living with dementia and describe a real gap in content available to them on the subject. Often, in the end stages of the disease many communication issues arise. Individuals lose their ability to speak or communicate effectively, are less likely to be able to express signs of pain, and will be generally more vulnerable than before. Staff need to know how to care for them and communicate better at this stage of life to make their last moments as comfortable and personal as possible. One staff noted that although there are some programs that target end of life care issues, there is a lack of programs about end of life specifically for residents with dementia and how the care for these individuals may require specialized approach to end of life care:

> *This facility has offered a lot of education on end of life care but specially dementia education end of life, dementia end of life care, not as much. Probably that's an area that's under, under… what's the word? It's not offered nearly… enough. Like, specifically to dementia. I think that would be a really, really good thing…Somebody at the end stage of dementia, there's no way they're going to be able to express pain... Chances are they have no communication ability whatsoever and so what does pain look like? What does an expression of pain look like with somebody whose extremely demented, extremely confused, not able to communicate whatsoever, other than your basic grimacing or you know, something that's obvious? (Aaron, Clinical Resource Nurse, p. 32-33)*

There are many palliative care programs for staff but there is a definite need to develop more programs with content specific to dementia and end of life care. This would promote compassion and understanding and be very good for staff dealing with this vulnerable population. Moreover, imagine a staff member having to provide care to someone with dementia who is dying, having no prior education or training about dementia care. While this facility appears to be staffed with consistent staff on their behavioural units, this is not always the case. Sometimes, when new staff are hired, they may be placed on a dementia unit where someone is dying and have to provide their care. Those staff members will be dually disadvantage. Not only will they need to begin learning how to interact with someone who has dementia but, they will also be facing the amplified communication challenges and pain management issues that come up for residents with dementia at the end of life. This is not fair to the staff, the residents, or the family members of the residents. One Aide reflected on the need for more courses about death and dying and suggested that it's good content for anyone in this field because it would teach workers about death from both a medical and spiritual background and aid them in providing more personalized care. She also suggested that courses on death and dying would benefit from including content on support and how staff can manage their feelings when they are caring for someone who is dying. She commented:

> *I think sometimes even for staff to learn about death and dying 'cause sometimes I think when someone passes on, I'm trying to be supportive to the family but then I'm crying because I've gotten so attached to a resident, you know. And I'm thinking, "Okay, I'm supposed to be tough here," but then I'm crying, so, yeah. But yeah, just more support about emotional issues and things like that. Support us you know, when someone's passing on or to deal with when we're getting hurt or there's critical incidents or seeing something happening between two residents. (Holly, Health Care Aide, p. 20-21)*

Residents become a large part of staff members' lives and so it is important for the facilities to educate and support them about issues surrounding death and dying to the best of their ability.

One final piece of subject matter or content that is missing from the current provision of education and training is information on medications used specifically to treat individuals with dementia. Nurses handing out the pills to residents need to be aware of why changes are made and what effects one drug may have over another. Specifically, there are a lot of different medications that are used to treat residents with dementia and it would be useful for staff to be more well versed on those and why some are more effective in some cases than others.It would also be good from a refreshing standpoint. There are so many drugs out there and it's good to stay on top of that:

> *I think that it'd be good to have more education and training on the different medications and what those medications are meant to do, and how they work because we go back and forth between different ones. We try this, doesn't work, we try this, we try this, we try that but I don't know if everyone is aware of all the differences of them all. (Susan, Clinical Resource Nurse, p. 27)*

Surprisingly, Health Care Aides expressed similar concerns about wanting to be more knowledgeable about medications used in long term care for behaviour control. In fact, all three Aides interviewed for this study felt that they would benefit from learning more about the medical side of things and about what different drugs do, why one is picked over another, and so on. They raised the concern that Nurses are more knowledgeable about these things and Aides are often left in the dark. In particular, they felt that they are not informed frequently enough when significant medication changes are made. They felt this was important because medications can explain a great deal about individual behaviours changing amongst residents. One Aide went as far as explaining why not knowing about drug interactions and the medical side causes stress in the day to day care giving for their residents:

> *I don't really understand the whole process of somebody being on the medication that they're on or how it might change their behaviour or what they're looking for when they put them on a certain medication. So sometimes I wish I knew a little bit more because I think we, we do sometimes get judgemental about it. Like, "Why aren't they taking their meds?" But we don't really understand the process. I don't really*

> *understand the process of somebody going on an antipsychotic or an antidepressant or whatever they're looking to maybe help with the behaviour. I don't understand that so I feel like maybe if we had a little bit more; or maybe we might not know that it's happened at all. Like, we may be struggling with a resident to provide care or just to; and we don't even know that they've been taken off all their medication and we're starting fresh [laughs]. Like, if we had maybe known that, we could maybe piece it together and think, "Oh well no. They did tell us you know, that Mr. So and So has been taken off all his meds so we can expect that his behaviour may change a bit and we're gonna-" Sometimes we're not told that. So I feel like if I had, if we had a little more communication and education to the wherewithal about that 'cause sometimes we can get a little, we can get upset about it because it affects our job. Like, it affects us day to day. Like, we're the ones getting hit, you know, or spit at. We don't really know why or all of a sudden he's changing so I think that would be helpful. (Melissa , Health Care Aide, p. 31-33)*

Medications play a very large role in long term care and can have profound effects on their users. It is important for direct care staff to be at least partially knowledgeable with the basics about common medications used so they can understand changes in their residents. Staff are frustrated when residents are aggressive or when they have a hard time providing their care and they deserve to understand if medications are playing a role in their struggles. This information will promote better communication among Nurses and Aides and prevent situations where Aides feel left in the dark about important care decisions. It will also encourage safety for staff and residents; an issue that will be addressed more in the following section.

Staff Key Theme #3: Staffing/Safety

Behavioural symptoms can be associated with different types of dementia and in some cases, residents who display more escalatory behaviours may progress to becoming aggressive. Staff need to be prepared to deal with these situations accordingly and so, it is important that current education and training methods contain information about safety. Often, education and training is focused on resident safety. What is becoming a new trend, is working with staff to promote their safety in these situations as well. In this facility, managerial staff recognized a need to prevent aggression towards staff and have taken a few precautions to begin addressing the issue. For example, because some units were experiencing lots of cases where staff were being hit, kicked, bitten, and so on, shift safety huddles were implemented. At shift change, nursing staff gather with the Clinical Resource Nurse and the manager and they discuss whats happening on the unit in regards to aggression and unsafe situations. It is an opportunity for staff to relay any issues they had with residents throughout the day who became violent or aggressive and brainstorm what they can do in future to prevent these situations. In some cases, what can be done is minor. They may look at specific staff approaches and see what can be altered to achieve the goal of providing care without aggression. However, if there is no change in resident behaviour, the managers and Clinical Resource Nurses will become more involved and explore alternative options. Essentially, the goal of these huddles is to be consistently working with care plans in order to provide care without those aggressive outbursts and staff injury. This facility has made a point to prioritize working with direct care staff through continually involving them in care decisions. They also acted promptly to offer some education when a newer behavioural unit for dementia was being opened by recognizing staff were going to be exposed to new challenges. This included the creation of a program within the facility that was offered for a short period of time when this transitioning to special care was happening. Staff were going to be asked to be in an environment where they would have to provide care to people with complex behaviours. Realizing there would be an increased chance of injury to staff, the facility implemented some education at that time:

> *I really felt at that time that it was important to give our Nursing staff more education in approach to dementia care approaches but also with the safety issue and so, the Nurse educator and myself came up with a one day program that we offered just temporarily for our staff. We incorporated one of the P.I.E.C.E.S modules for Health Care Aides and appropriated sort of a, sort of an abbreviated version of Violence [Prevention] is 9/10th of the Law. We concluded another presentation that another one of our Clinical Nurse Specialists had put together about dementia care approach as well so, made that into a one day because I just really felt like we weren't offering enough to our staff. That one is the one that's specifically we created, the Clinical Nurse Educator and I created for the behaviour unit and dementia care unit staff.(Aaron, Clinical Resource Nurse, p. 18)*

Since then, they have implemented more communication throughout the shifts in order to work as a team to care for more challenging residents. It is through communication or the transmission of information, that staff are able to receive better information and become more knowledgeable and prepared. Without effective communication, education suffers. These safety huddles are currently being utilized on all behavioural units in this facility to promote better care provision and to reduce the issues surrounding staff safety that are commonly experienced in these settings. Staff injury is very serious and there is no reason why they should have to be subjected to an unsafe work environment. In other professions, safety issues are unacceptable and workers maintain the right to not have to work in an unsafe environment. It should be no different here. Yes, residents with dementia are unpredictable and may act out aggressively but that is why continually examining safety issues is important. The care still needs to get done but it should and needs to be done in a way that is safe for everyone. Many safety issues can be avoided if staff are educated on dementia and understand how and when to appropriately approach a resident who is showing signs of aggression. This education in itself, can be challenging but having uneducated workers attempting to provide care without a solid framework is not acceptable. One participant commented on the importance of education and safety:

> *I think it's always better to keep working with people doing the direct care for safety reasons, you know? I always want to continue the education for them cause the most educated and trained person can still get into situations that aren't pleasant. (Susan, Clinical Resource Nurse, p. 8)*

These environments can be unpredictable and thus, equipping staff with the tools they need is paramount to quality and safe care provision. Moreover, despite the widely recognized need for more staffing on these units, the facility is doing its best to implement what measures it can to protect the safety of direct care staff. Firstly, staff on the unit are provided a panic button. The purpose of this button is to allow staff to call for help in cases where they may feel their safety is being compromised:

> *We're supposed to pull it if we feel unsafe or somebody's getting really violent. We're supposed to pull it and it makes a shrieking to let the staff know… And this actually, if it pushes, security will go down to security and they might call up and say, "There's an alarm going off." (Melissa, Health Care Aide, p. 21-22)*

This is useful for situations where staff may inadvertently become placed in a situation where they are backed into a corner by an aggressive resident and are unable to leave safely. It is also useful for situations where unexpected outbursts occur and staff require assistance. Another safety measure that has been put in place is the, "Blue Dot Program." This is a program that places a blue dot outside of the rooms of residents who have a history of becoming more aggressive or who pose more of a challenge to staff to provide care. The blue dot serves as a warning sign for staff and others that before entering the room, necessary precautions must be taken. Either more than one staff member is required or this particular individual requires more specified care. Staff are asked to investigate why the resident has a blue dot before entering the room and before preforming any care alone to promote safety. One staff explained the goal of the Blue Dot Program and how it works:

> *Basically our goal was to just make sure… communicate with staff that there's potential with this person that there could be agitation and potentially aggression during care and to provide a more specific care plan like we need to, you need to have two people present or at least available to assist when providing care to this resident. At times we've gone a step beyond that and we'll explain, we actually give direction on how to provide care step by step for that person. So that's, that's sort of like giving the more concrete direction to staff. This is what we've established as the care plan and this is what you need to do. (Aaron, Clinical Resource Nurse, p. 22-23)*

The information for people investigating a blue dot resident will include cues like, "hits, kicks, punches" so that staff are aware of possible safety concerns. It also contains information about medications they may need when they are agitated in order to preform care, and so on. Staff appreciated being given this tool because it promoted better communication about what is happening with aggressive residents. They felt more prepared to provide care in situations where they were informed. The blue dot is helpful for staff and it also serves as a reminder to visitors to be careful before entering. Staff seemed very positive when talking about this program:

> *When there's a Blue Dot then we know we have to go in with two people and sometimes three people so that's a good thing. And then if new staff come on they know that, "Oh, okay. We better find out about this person. Why are they a but dot and what can we do to provide safe care to the residents and for ourselves and not get hurt?" Yeah. So that's a good thing. That's a really good thing. (Holly, Health Care Aide, p. 22)*

Implementing this program was a step in the right direction but it is not the only safety measure in place. Sometimes residents become challenging to the point where the staff assigned to the unit and that particular resident cannot manage the workload on top of having to provide care to the remainder of residents. Where this is the case, the second measure of a one-to-one care provider is sometimes implemented:

> *We may have somewhat we call non-funded positions and those are positions that are on a temporary basis for people with severe challenging behaviours where they need closer supervision so they may have either patient watch or a one-to-one. So, on this*

> *unit right now we have one lady that had twenty-four hour one-to-one because she's quite violent. So she has an additional one person staffing. That can vary from day to day. (Meredith, Managerial Staff, p. 10-11)*

One-to-one care helps workers by relieving some of the pressure they may feel when trying to manage their workload. It allows them to be less concerned about one particular resident displaying more challenging behaviours. Since that person will no longer be monopolizing all of their time, they can continue to provide care more safely to other residents on the unit, knowing that someone is watching that particular resident. Thirdly, the facility recognized a need for more supervision on these units and implemented a hallway monitor on one as a trial. Essentially, the hall monitor serves as an extra person on the unit to watch for conflict among residents in the halls. They are also there to prevent unnecessary falls and to keep a general eye on the residents who are not receiving direct care at the moment. This position was implemented because at that time, the facility recognized there was a need for more staff and supervision:

> *You know like, there's such a need for staff. I mean we have, we have managed to have hallway monitor on evenings on the evening shift on our two behavioural units and that basically is a Health Care Aide who the assignment is not to provide direct care in residents rooms but just basically oversee the unit, assist residents in the public spaces, like in the hallways or in the dining room because there's really very limited supervision when the staff is providing care. (Aaron, Clinical Resource Nurse, p. 27)*

This position is a semi-permanent to permanent position and will be kept based on the need for it but because there is such a need for staff in long term care, the one Clinical Resource Nurse commented that they doubt to see a day where this position will not be needed. Furthermore, having more supervision is important from a safety standpoint. Having that extra person there will help decrease resident to resident aggression and falls when other staff are occupied in other places and cannot keep an eye on all of the other residents. Lastly, a major strength in the facility's current approach comes from their staff members who offer a lot of support to each other in times where they are dealing with more aggressive residents:

> *They're very supportive to one another. Extremely supportive. Even when somebody gets hit, its like, "Oh, are you okay?" You know, "I'm so sorry you got hit today. Is there anything I can do to help you?" You know, when somebody gets hit on the unit you know, we discuss it. We talk about it. We say, "Okay, how can we do it better?" so you know, somebody's not going to get hit next time. You know? So there's a lot of discussion. (Meredith, Managerial Staff, p. 34)*

Staff well being is prioritized and safety concerns are taken very seriously. Staff also do the best they can to help each other avoid situations where there is potential to get hurt. If a resident is more comfortable with one particular person but they are on another worker's care list who struggles with that resident, that individual they will offer to provide the care instead:

> *If a person's resistive to an idea such as getting dressed, or going for a bath, or going to the washroom, then you know, ten minutes can make all the difference in the world so definitely re-approach. A different face making the offer. Definitely try that. You know we have enough staff on the unit that you know, they'll take turns. They'll kind of help each other out you know. Would this person feel more comfortable with a female? Would they feel more comfortable with a male? Um, are there racist issues? Do we need to you know, look at you know, what race of person is offering the care or trying to be… but really, always encouraging staff to be a friend and not just be a direct care provider but to be a friend to the resident and to present the idea of providing care as just a friend helping you out rather than, "I'm here to help you. Let's go and do this." (Aaron, Clinical Resource Nurse, p. 21-22)*

So it's all about a teamwork approach and understanding what more can be done over time to add to the growth of a more safe work environment. In talking with staff, it became clear that safety is highly prioritized. Unfortunately, even with this prioritization of safety, there are still safety issues within long term care and within dementia specific units especially. Many of these issues seem to be linked to issues surrounding staffing:

> *I think a lot of the staff members feel that if we had more staff we would be better equip to deal with the residents with dementia. (Susan, Clinical Resource Nurse, p. 16)*

Staffing has been and continues to be a major downfall in the provision of a higher quality of care for residents living with dementia in long term care and in long term care in general. There never seem to be enough hands to take care of residents and the addition of dementia and specifically, more challenging individuals living with dementia only adds to the stressful nature of having to provide the care. It also adds to the much more complex issue of staff safety. Every single individual in this study had something to say about staffing or the lack of staffing. Staff were concerned because on a unit with people with behaviour problems, sometimes there are not enough people to manage the workload, especially on days where more difficult resident behaviours are high. They also express concern for their safety in unexpected situations of aggression when there is little staff:

> *There's been times where, you know, a resident, you're not sure. You come out of a room and a resident's really agitated and grabs your arm and you're trying to… actually it just happened. You're trying to get free and the other staff might be busy and you just have to yell, "Help!" [laughs] and see who comes out. So there is times… That, yeah. And there has been times when, like I said, you learn as you go and certain residents, I've been caught in the corner and someone's coming at me so you learn, okay. I never leave myself, always leave myself in a doorway and unless there's someone with me, I'm never going into the room past them because I'm putting myself at risk of being caught in the corner with no where to go. (Melissa , Health Care Aide, p. 20-21)*

As mentioned above, the Blue Dot Program was put in place to help ease this safety issue but it still doesn't make up for the lack of eyes or hands on the units in general. If there are only two Aides on the floor with one Nurse and one of the Aides is on a break, and someone is providing care in a room, that leaves one person and often, a lot of residents require two staff members for transfers or care. Further to this, if staff are busy providing care, there will be many residents who are not being monitored at all. One Aide commented on this and her safety concerns:

> *If you need two people to go in and provide care and then the Nurse is trying to give pills, and then there's nobody else there to watch the dynamics on the unit, then it sometimes feels not safe because you don't know what's going on in the hallway and then you hear, "Help!" Like, those moments [laughs] are stressful. (Melissa, Health Care Aide, p. 20)*

Understaffing is unsafe for the workers and residents and frankly irresponsible from a safety standpoint. No one will benefit if something serious happens while there is not enough staff on the floor. Similar concerns were raised when a discussion about different shifts was brought up. Common practice for a lot of long term care facilities is that staffing tends to go down in the evenings and on night shifts. This is particularly concerning because staff are already struggling with preforming their care duties when they have the maximum allotted staff on at a time. Furthermore, safety is a huge concern on dementia care units when you take staff away. One Aide who works nights expressed her concerns:

> *We have six bed alarms. Like, you can only be in one place at one time and sometimes, that one person will monopolize a lot of your time so you don't know what's going on out there. (Shirley, Health Care Aide, p. 19)*

And, even though one-to-one workers are being periodically given, it is not a permanent solution. The reality of the situation is that there are too many residents with unpredictable behaviours and not enough staff to care for them safely. Implementation of one-to-one caregivers is a great idea but more long term solutions need to be put in place. The hallway monitor position in place on one of the units in this facility was a great idea however, not every unit within has this luxury despite the overall indication that more staff is needed:

> *The fact that we have needed to put these hallway monitors in place is an indication that you know, there's not enough eyes around. There's not enough bodies. There's not enough hands to assist the residents who need it. And of course, residents with dementia require so much re-assurance and assistance and close contact and supervision so yeah. We could do with lots more staff…Similarly to the hallway monitor, to me, it's an indication that you know, it's it's just kind of, if you don't have enough staff then you are going to be needing more of those one to ones, hallway monitors, and things to try and fill the gaps. (Aaron, Clinical Resource Nurse, p. 29)*

Further to that, it is hard to develop a good staffing model when all units are staffed differently. In this facility, staffing for the units is based on a variety of factors: how small or large the unit is, how difficult the behaviours on the unit are, the overall care requirements of residents, and so on. The facility follows the staffing regulations given to them by the WRHA and implements things like hallway monitors or one-to-one staffing when there is available funding or a need for it and they are given the go ahead to do so. Staffing is a huge safety concern because these units are also very busy at times depending on what's happening that day, the dynamics of the unit, or how the residents are behaving. One staff describes the hectic nature of working in this type of environment:

> *You try to work as a team but sometimes that doesn't always work out because someone else is behind or you know? All it takes is someone to get sick or a death, anything and it can just change the whole, the whole situation of your day, what you thought it was going to be. It could be totally different. (Shirley, Health Care Aide, p. 25)*

When these types of situations come up, it can be very stressful for direct care staff who are already struggling with the manpower they have. Dealing with unexpected situations as they come up is part of the job but doing so may sometimes mean that staff have less time to get the same level of care tasks done. As a result, the quality of care my be compromised and the chance of staff being harmed may increase. If staff aren't given appropriate time to approach residents with dementia they run the risk of upsetting the person and escalating or even prompting challenging behaviour unwillingly. Staff are more likely to get hurt where this is the case and the facility does not want to see that. In fact, this facility encourages leniency in care and waiting until residents are ready for staff to approach them:

> *We don't want to see any resident get hurt because someone is trying to force care on them. We also don't want staff to get hurt from the resident by trying to force care. So, we're really trying to work as a team right now to relieve these stressors that the staff feel when they can't preform care. Sometimes it just takes getting them a PRN or two hours you know? Let them have a different thought process going on and then re-approach later. (Susan, Clinical Resource Nurse, p. 21)*

These workers have a duty to provide care and these residents have a right to receive it to the highest quality possible but there just doesn't always seem to be enough time. This is unfortunate because personalized care and taking one's time can help to achieve more compliance in delivering care to residents. More personalized care also has the potential to increase quality of life for residents. Unfortunately, sometimes staff struggle to preform basic care and find themselves short of time for more personalized interactions:

> *They don't necessarily have the time to sit down and do those things… But, those are things that you can use to minimize, maybe a potentially explosive situation, right? So, I think people escalate in facilities like this a lot quicker because you don't have that manpower, or that person doing that. Then they're stuck yelling in the hallway, "Well help me, well help me" and you know, then they get more agitated and then, then you're dealing, you know, then they have a lot of attention when it's sort of too late. So…yeah. (Charlotte, Managerial Staff, p. 21)*

Better staffing ratios is imperative for a higher quality of care and for increasing safety for staff and residents. When staff are less rushed, they will be able to provide more person centered care and have a better chance of providing care without aggression since they will have more time for approach and re-approach. Managers are frustrated because they can only staff what they are allowed through the budget that is available to them. These units are also allotted similar staffing ratios to regular personal care units which can be problematic because residents with dementia can often require a higher level of care:

> *It's a little difficult when you know, you can't get an increased budget for staffing and you sort of have to work with what you have. (Charlotte, Managerial Staff, p. 10)*

Care levels in long term care units are also quite unpredictable and may fluctuate very quickly. A resident who is walking one day, may lose the ability to walk the next. This will increase their care level significantly to where they will need two people for transferring; previously they may have only needed one person. In any given situation where these care levels increase so does the demand for staff to adapt. Units will often experience, "heavy" times where the care demands are high but the staff ratios are the same. This means staff must juggle a heavier workload than previously. One manager commented:

> *It's heavier now. When we first sort of opened there was a lot of people that were walking that have now deteriorated to the point where they need a mechanical lift, they need to be fed. And then the people that are ambulatory have behaviours we're managing, right? So the workload is a lot here. We, other than the day shift, I have exactly the same staff as the regular PCH units. (Casey, Managerial Staff, p. 17-18)*

Safety also becomes an issue when float staff are brought on the units to cover for more regular staff. Sometimes, these staff aren't as familiar with how to approach these residents which may put them behind in preforming care and gaining compliance. It can be frustrating for them, the residents, and the more frequent staff:

> *If I have float staff on that makes it really, like they become kind of disgruntled if there's lots of floats on because they don't know the routine, they don't know the residents and that puts them behind. And that; and it really does cause a bit of chaos, right? Because that person doesn't know how to manage the resident so, that's their other complaint. (Casey, Managerial Staff, p. 36)*

When this subject came up, one Aide felt that dementia specific education and training prior to entry on the unit might be beneficial, especially for people less familiar with the disease:

> *There is so many different challenges that; and sometimes if you're not sure how to approach a resident or if you approach somebody the wrong way when they're a little bit upset, it can blow up in your face. I mean, you could get hit or… so I think sort of more training, more working with somebody for a longer period of time just to get that comfortable feeling. 'Cause sometimes people come to our unit, they may pick up a couple of shifts, and they don't come back because it's just not-either they're afraid or they're not comfortable, or they just, you know? So, so I think maybe sometimes if you had a bit of a longer time to adapt to working on the floor it might help? But then again, it might just not be for everybody [laughs]. I don't know. (Melissa, Health Care Aide, p. 11-12)*

The safety concern here is huge. Having unexperienced and undereducated staff put on a unit with residents who display escalatory and sometimes unpredictable behaviours is not safe for the staff or the residents. Staff should be able to feel comfortable in the workplace and residents' daily routines should not suffer from staff who are unfamiliar with how to communicate and provide their care.

One final safety concern that came up had to do with receiving training on how staff can protect themselves. As mentioned before, programs like this exist but the availability of them has been fairly limited. By understanding the proper ways to protect themselves through holds and non-violent intervention staff may feel more safe in the workplace:

> *They haven't had Crisis Intervention for I don't know how long it's been. That's something that, that needs to be done because there's so many people who, who forget and especially with our population of people who physical are, you know, have physical outbursts, so you have to have, find a way to restrain them without harming yourself and without harming them. (Shirley, Health Care Aide, p. 33)*

Staff also want to be given more help with how to keep up to date on these techniques. One went as far as to suggest that the program itself, needs to be more clear on what steps to take when what they're doing isn't working:

> *We've been given like, sort of like the non-violent how to get out if somebody grabs or goes to choke you or somebody grabs your arms a certain way but sometimes they really, they just don't work. I, like, I've tried different ways, if somebody has your arm and they're twisting it… I, I've tried and sometimes it just. It doesn't work. (Melissa, Health Care Aide, p. 21)*

Non violent training and injury prevention training would also be particularly useful for float staff and people who are less comfortable on the units. It was mentioned in a previous section that some float staff are not familiar with how to execute proper holding techniques. This has implications on staff and resident safety. Staff working in potentially harmful environments should be equipped with these skills. When you have more staff, you have more hands to help and more eyes to monitor. When you have more educated staff with a variety of tools to use, they are less likely to get hurt in the workplace. They will also feel more comfortable with working with residents with who display more unpredictable behaviours if they have some form of self defence or protection to fall back on. This will keep themselves and the residents safer. Staff safety is very important and the education and training needs to incorporate more subject matter on the issue

Staff Key Theme #4: Personhood/Dignity

> *These are still people. They're still human beings. They're still humans so they deserve dignity. They deserve compassion. They, they deserve all that even though they have no clue what that is or why it is, they still… that's, that's their, their human right. They're entitled to it. (Shirley, Health Care Aide, p. 44-45)*

Every individual in long term care has had a lifetime of experiences of their own. They are people and need to be treated no less. Person centered care refers to care that focus on the individual as a human being and was mentioned in the literature review in greater detail. This is a paramount approach for staff in long term care when they are working with individuals living with dementia. The facility in this study prided itself on doing its best to maintain a resident’s dignity by taking a personalized approach to care and through providing staff with education that emphasized the importance of individualized care. Some of the education available for staff also emphasized the variations of dementias and how they play into the need to provide unique approaches to care on an individual basis. Some residents may strike out while others may experience memory loss with no aggression, some may maintain their long term memory, while others will not. There are so many presentations of dementia and they vary person to person. This is why staff need to be able to adapt to each resident's care needs and be familiar with different forms of approach for different forms of dementia. Staff in this study appeared to understand the importance of approach and applauded programs that gave them more skills to use to provide care to different residents. In the section about education and training content, staff really appreciated being given the information and tools they needed to be able to understand that sometimes when a resident is displaying a behaviour they may actually be trying to communicate a need or be expressing their pain. They appreciated being given a framework that focused on individualism and caring for residents on a person to person basis.

Staff are passionate about their work and want to provide the best care they can. When questioned about the most challenging aspect of providing care, staff members responded in similar ways. A lot of times it comes down to learning how to deal with situations where residents pose more difficulty in receiving the staff's care. When residents are resistive or aggressive, it is especially difficult. Even so, staff were pleased with the fact that the facility was doing its best to provide them with the tools they needed to adapt and become better at using an individual's personhood and individualism to get the care done:

> *We have a lot of residents who are very resistive to care and it's a challenge to figure out a good care plan for the resident. A lot of the time it takes a team to get the care done. Sometimes it will take a Nurse and two Health Care Aides to get the care done so then part of the education there is making a good care plan and making sure everyone is aware of the care plan for how we're going to get care done for this person. (Susan, Clinical Resource Nurse, p. 20)*
>
> *We're learning now, especially with people who are aggressive,"Hey." Like you walk into a room or something and you say, "this is so and so", sometimes one person might have to hold the hands and the other person might have to, like, sometimes you have three people in the room and one person will have to sing to the resident because the resident likes music. (Holly, Health Care Aide, p. 24-25)*

By utilizing aspects of a person's life; in this case, the individual's love of music, staff are able to provide better care:

> *It's just kind of trying to communicate with other people and ourselves how to deal with the people who are aggressive and how to notify, you know? Yeah. People and the families and stuff like that, yeah. And how, and also put in the care plan what each individual person, how you can do care on them because they're all so different. (Holly, Health Care Aide, p. 24)*

It's these differences and the individuality of of each resident that makes education and training on personhood and person centered care all the more important. It was really great to see how staff members spoke about dealing with the care of more difficult individuals. They stressed having a level headed temperament and frequently mentioned approach and how the residents can sense their moods. They explained that developing a relationship with a resident in such a way that allows them to achieve a person centered care approach takes time and begins with their energy and approach:

> *The most valuable tool for success in working with them is your approach and your energy. If you're pleasant and you talk pleasant and you always smile, they feel safe. They can't say it but they know and if you're stressed... We wanna treat them like family and that's our, our, kind of our thing on... We are a family and all of these Health Care Aides and Nurses care about these residents and I care about these residents so when families come to me with a concern, "And my dad blah blah blah," and I say, "You know what? We really care about your dad. He's like family to us. We see him everyday. We want what's best for him too," and then you build that trust, right?…We really care here and we wanna do what's best for our residents. (Casey, Managerial Staff, p. 30-31)*
>
> *I don't know how it is but they can sense your vibe. So, if you've had a bad night, you've had some stress at home. When you walk into their room they can feel that. I don't know how but honestly, it's the truth. If you go in there and you're angry and you're frustrated they sense that and they react to that. If you go in there and you're happy and you're whatever then they're more compliant… Yet their mind. They can't put two cents, two words together, that they still have that ability to sense that emotion which is really, really interesting. (Shirley, Health Care Aide, p. 16)*
>
> *If you go in there with a chip on your shoulder, you know, your probably going to… things aren't going to be very good. But then sometimes you could be really happy and depending on the person's day, they could be like [sarcastically], "Oh aren't you little Mrs. Sunshine," and that. But, most of the time you know, just being nice and friendly works. (Holly, Health Care Aide, p. 37-38)*

These responses indicate that training and education is effective. Staff learn over time to respect the individuality of residents and adapt to their environment. They learn to adjust their care based on the individual and how the individual is feeling. They do not force, but encourage and they recognize the need for a calm temperament. No doubt, these techniques in action assist in making the day to day lives of both staff and residents much better. It also helps that the staff in this study seem to be strongly invested in their residents and passionate about dementia care.

Referring to a question on why managers think staff stay on units like this for so long, one commented:

> *In my opinion, what makes them stay is the fact that they love the residents with dementia, that they feel that they can make a difference in that person's life. They enjoy spending that one-on-one time with the residents. (Meredith, Managerial Staff, p. 33)*

The Health Care Aides confirmed this. When asked a similar question about why they continue to work in an environment full of stressors they replied without hesitation:

> *Well, 'cause it makes me be an advocate; that I can be there for people who can't speak for themselves and someone needs to be there for people who can't speak for themselves. Some people can and some people are at a level of their dementia where they can't and they need people who are going to treat them like a family member and treat them with love, and respect, and dignity. That's, you know? And, treat someone with, how I'd want my family treated. I've had relatives in this situation and yeah. I would want them to be treated like I want my Mom treated, or my dad, or whatever. (Holly, Health Care Aide, p. 29)*
>
> *I really enjoy it... There have been times where it's gotten… the stress level is just... There's certain times when I've felt like maybe it's time to leave and then, it gets better. Like, there's just moments and sometimes you get a resident that's really, really challenging and like I said, where you feel like you're not giving the care that you want to give. It gets, well I get like that anyway. I feel like I'm not doing my job. Like, if I leave work, I feel like I didn't do my job and so, there has been times but then you just ride it out. It gets better [laughs]. And I, I like, I enjoy working with people with Alzheimer's. They really need people that are kind and patient and I think I have all the qualities to work here, so. (Melissa, Health Care Aide, p. 12-13)*

Endless amounts of education and training can be provided but at the end of the day, having staff who are passionate about their work and the residents is equally as important. Education and training on personhood and having a workplace that encourages and promotes person centered care is paramount to the success of delivering person centered care. Unfortunately, maintaining resident dignity and personhood does not go without it's challenges in long term care and many staff feel frustrated with different obstacles such as time or staffing that prevent them from delivering the quality care they want to give their residents:

> *I, honestly, I feel that personal care is just warehousing bodies… That's my evaluation. We're just warehousing bodies which is sad because we're all human and it just seems so. I don't know what the right word is but it just seems so wrong. That's basically all we're doing. Is just warehousing bodies. So I don't know what kind of education would fix that. (Shirley, Health Care Aide, p. 26)*

Staff want to provide person centered care but face many barriers in doing so. In particular, Health Care Aides are faced with the very large task of providing hands on care under large stress in these environments. Firstly, and most often spoke about, Aides feel like sometimes they lack the actual time to provide personalized care because they are overwhelmed with other tasks they need to preform before their shift is over:

> *It's a heavy workload. It's hard for Health Care Aides I find, not to be task-oriented to get done what they need to get done. Sometimes I think they feel stuck in hard place with people with dementia on getting it done and allowing all that time for re-approach, coming back, letting them refuse, you know, taking twenty minutes extra to do each resident is hard on the Health Care Aides. (Susan, Clinical Resource Nurse, p. 17)*

It's a frustrating position for the Aides because they do feel stuck sometimes. They want to be able to utilize P.I.E.C.E.S and all the knowledge they have gained from learning about person centered care but they just simply don't always have the time for it. The workload is very heavy for Aides which makes it extremely difficult to be able to spend a few extra moments with residents before hurrying off to the next room, or to do a little extra in their day to day tasks:

> *When it's a super, super, crazy, busy, day, I sometimes go home and say, "Oh my gosh, I didn't have time to do this or this." It might not even be to do with the resident. It might be even like for example, making their room look neat and tidy. 'Cause some people just throw clothes in the coset or whatever. Or just even, like little things with the resident like saying, "Awe. I really wanted to give them a good manicure," you know? Like, to make their nails look pretty or something, you know?*

> *Things like that. But, it's so hard because we don't always have time or we can't afford to have one staff member off the unit. (Holly, Health Care Aide, p. 33-34)*

It's also frustrating for them to utilize a good person centered care framework when they have to deal with more resistive or aggressive residents under these time and staffing pressures. In order to provide the care the resdients need and deserve, staff need to take more time with them and implement what they've learned about approach and the different types of dementia in order to provide care. When residents continually refuse it puts staff behind. They know they need to leave time for re-approach but struggle with accomplishing tasks sometimes:

> *With this population, you may want to get them dressed and they may be willing and then all of a sudden they're gonna say, "No. No leave me alone." Or then they're half dressed in the hall. Sometimes they're naked, they're full of feces, their walking down the hall [laughs]. To some people, that would be horrifying but on our unit, that's, it's acceptable. You, you can't, you can't fight it. Their… each individual is an individual so you try to plan your care plan around them. (Shirley, Health Care Aide, p. 36-37)*

> *Your goal is to have them look the way they would look if they didn't have the disease and care for them and you want to give them that care but then, when they're aggressive and you, you just can't do that and you know they're walking down the hall and they're looking disheveled and they don't look cared for… I find that challenging...'cause you just want to give that care but sometimes it's not working out that way [laughs]. (Melissa, Health Care Aide, p. 8-9)*

It is also difficult for staff to accept that they cannot always gain compliance right away and that they may have to wait and give that time for re-approach. In particular, many find it challenging to let residents walk around without care because they are fearful of what people coming on the the unit will think if they see someone not dressed or who looks dishevelled. They care highly for the residents and do not want a family member to think they are not trying their best or that they are lazy and avoiding dealing with certain residents. Staff in this study were clearly high achieving and cared a lot for their residents. They want to do right by those they care for but given the way long term care is set up, it makes it difficult to provide the quality of care they want in the timeline they have and with the resources they have. At several points, Health Care Aides referenced the struggle of juggling the appropriate times for re-approach and the general struggles they experience working with more aggressive residents. They find it especially difficult during times when a resident's dignity is in question. For example, leaving time to re-approach a resident who has soiled themselves or who has become incontinent can be stressful for some workers because they want to maintain the dignity of the resident but must also do so in a dignified and non-forceful way. Residents have personal hygiene needs that need to be met and it can be a really hard balance between providing care and allowing sufficient time for re-approach to do so. This is why understanding resident cues is important as well as knowing when an appropriate time is to attempt to provide care to more aggressive residents. Education and training about these issues will assist staff in making those hard judgement calls in the workplace and assist them in preventing further aggression by giving them the tools they need to communicate in a non threatening and effective way. If the staff working have not been given any training, completing basic care tasks may prove to be quite difficult in situations where residents display more difficult behaviours. Early preparation is very important. Staff coming into this type of environment need to be aware of what types of situations they may find themselves in because as one Health Care Aide noted, this is not always the case:

> *A lot of people when they come into this job... will take things personally. They don't realize that some people with dementia, they have aggression, different personality changes so that's kind of a big eye opener. When you're seeing this at first you're like, "Oh my goodness. Someone's hitting me or someone's swearing at me," but then after a while, you know, like they should warn people about that. Not to take it personally and this is the disease and not the person. So I think that would have been*

> *more helpful because it's kind of a pretty big eye opener. (Holly, Health Care Aide, p. 6)*

Coming to understand that there are these challenges with behaviours is often a detouring factor for some individuals who come on the unit as a float or casual staff member for replacement. They may be uncomfortable and not want to work in the environment anymore. Uneducated and untrained staff also pose many issues for more frequent staff. If they aren't aware of proper approaching techniques and are not use to dealing with this population it may set the unit behind. It may also have negative effects on the actual care that residents are receiving. One Aide commented on the importance of communication and became quite upset in cases where people were not sure about how to treat and speak to the residents:

> *Some people just don't know how to talk to our residents and can be very disrespectful… It's really irritating… Some people just aren't cut out to work here and then some people... maybe it's not adequate training... I wish that everyone could take a course to do with dementia and every form of dementia because there's so many different things and it's like, wow. Sometimes you can pin it. Like, that's how someone with Korsakoff's is you know and like different behaviours and different things and how to deal with certain things. (Holly, Health Care Aide, p. 27-28)*

She felt confident that training could make a big difference in the care residents received but also suggested that a certain temperament and type of person is better suited for this particular environment. A staff member who is highly educated may still struggle in certain situations and if they aren't the type of person who is calm and collected or who is someone that let's things bother them easily, they may experience more difficulty preforming care and gaining compliance from residents. Furthermore, it was mentioned previously that residents pick up on a person's energy. With this, having a staff member who is more irritable or impatient can create alternative issues and barriers to providing more person centered care. When asked about her experience with working with less understanding staff, the same Health Care Aide became fairly emotional and rightfully so:

> *It makes me angry. It makes me sad for the resident. Yeah. It makes me angry and sad 'cause I, like I've been here for twenty-five years and I've been here because I love my job and I love the residents and it just breaks my heart and it makes my day crummy, sorry [tears up], when I'm working with people like that. It's like, "Why are you doing this? Leave our floor." You know? "You don't belong here." (Holly, Health Care Aide, p. 28)*

Other staff who participated in this study shared similar concerns about this and also drew attention to another issue about training. When float staff or newer staff are shadowing more experienced staff, the more experienced staff have no knowledge of how extensive their prior training has been, if any. They are also unaware of how much education on dementia they've had. This makes it difficult for staff to provide well rounded training since they have no information to go on aside from asking the person. It makes it more difficult for new staff to adapt to this type of care if they haven't been able to receive prior education or training. One Aide suggested that the timing of training would be significant to look into:

> *Sometimes I'm not sure how much they've had for training so I think they get, they might get their P.I.E.C.E.S workshop and that stuff after they're hired on our floor which… I don't know if that's helpful or not. (Melissa, Health Care Aide, p. 14-15)*

It really doesn't make much sense to have people learn blindly and completely on the job because it affects the person centered care framework in a very negative way. The staff suffer, the residents suffer, and the families suffer. Equipping staff before entering the workspace on the different types of dementias, approach, and general topics about dementia will better prepare staff to provide more dignified person cenetered care.

The Family Members

The Family Members' Themes	
Support/Self Learning	Family members enjoy a support group and the educational piece that is incorporated in it once a month but have found that the best support they have received has been through friends and families. They identified that most of their learning about the disease was done on their own while taking care of their family member outside of the facility. They are thankful for the opportunities they receive from the facility but many take education into their own hands and informally learn on their own. Most family participants felt that education on dementia would have benefited them more prior to when their family members were admitted but appreciate the opportunities provided for support and learning.
Staffing	Family members are concerned about staffing in the facility. Predominately, they identify staff as seeming rushed and overworked which raises safety concerns. Families worry about the safety of staff when there are not enough and they worry about the safety of residents who are not being monitored enough. Most visibly noticeable to families, was the decrease in staff over the weekends or holidays.
Personhood and Engagement	Family members recognize staff struggles but applaud them for doing their best to remain engaged in person centered care. They also express their joy about staff taking time to build a rapport with them as well as their family member in care. They felt that this environment created a sense of home and family and gave them some peace of mind.

Three key themes were identified in the family member's responses. These key themes were: Support/Self Learning, Staffing, and Personhood/Engagement.

Family Members Key Theme #1: Support/Self Learning

For the family members of this study, the topic of support and education surfaced frequently. As mentioned previously, when a new resident is admitted into this facility, family members receive informational brochures about the unit and the disease. They are also given contact information for the Alzheimer's Society and invited to participate in a monthly support group with staff and other family members. Family members in this study felt supported and were generally pleased with what information was made available to them upon new admission. Aside from receiving various pamphlets about the facility, the units, the Alzheimer's Society, and an invitation to attend the support group every month, staff encourage family members to approach them with any questions or concerns they have at any time. Families may not always be willing or want to attend the support group right away but staff still make themselves available if and when families need assistance. If family members approach staff with issues, they are directed to whichever resource(s) the managerial staff deem fit to assist them. Managers will also assist with any referrals families may need whether it be for the Alzheimer's Society or other relevant organizations. Whether they chose to attend or not, family members in this study were appreciative of the fact that there was a continuing opportunity for them to receive support and information in the monthly support group. Overall, participants felt that this group was a good opportunity for people with similar issues and problems or experiences to speak with one another in the hopes of taking something valuable away from the experience. There are also opportunities to speak with staff members as facility representatives are present at the meetings for support as well. Family members are welcomed and encouraged to bring up concerns or questions in this group and invited to learn something each month as a different topic on dementia is introduced. Though not every topic is new to those who attend, family members still enjoy the opportunity to learn more about the disease and find the group to be quite informative:

> *I just found it was, it was… informative in the extent that what could, you know, what you could expect… it educates you like… last time I went it was the first stages and then the second stages and um.. and you know, the different stages and what to look for. (Dorothy, Family Member, p. 12-13)*

The facility does its best to use the support group as a means to not only offer families with the support they need, but to also give them some exposure to information about dementia they otherwise might not get. The managers and direct care staff of the units do their best to provide families with the support they need as soon as residents are admitted and make clear to them, the what resources are currently available for them. They provide the group with information on various educational topics. This includes talking about the disease itself, the different types of dementia, some of what can be expected in the end stages of dementia, oral care issues, and other topics based on interest from the group. The facility's focus is to bring family members together to support one another through their similar journeys. They do this through the support group and through providing them with those opportunities to educate themselves further. Based on their individual levels of interest, different topics are selected for discussion at the support group. Families are not held back from any opportunities to receive support through education if they desire it. Interestingly enough, however, was that despite the encouragement of the facility to support families through education, many family members did not expect the facility to be responsible for providing education and did not think it was entirely necessary. That is not to say that family members were unappreciative. In fact, it was quite the opposite. Family members applauded the efforts of the facility but also relied more on themselves for seeking out education. For example, one family member thoroughly enjoyed the support group but also felt that it was her own responsibility to seek out education:

> *I don't think the facility in this case is responsible to me to provide me with educational opportunities… I think they need to be accessible… I can be responsible for searching out my own education. (Mable, Family Member, p. 26)*

This was accompanied by several other family members who were in agreement and who felt strongly that they were sufficiently supported outside of the facility. Because of these outside sources of support, they felt the facility should be under no obligation to provide them with education and support:

> *I don't feel I need that much support. I've got a very supportive family that help me as well and we talk quite freely about it and about things in the paper and we're going; like we do the Alzheimer's walk once a year and this group [the facility provided group]- well they're both very good groups but this one is a more social group and the other one [Alzheimer's Society Support Group] is more… a serious type group where you don't talk quite as much about simple things or family things. (Beth, Family Member, p. 11)*

It is also important to note that some of the family members in this study had backgrounds in the health care field and were familiar with caring for individuals living with dementia in their own working careers. For these individuals, the support group didn't seem to be as effective in providing them with new information but instead, gave them an opportunity to support other family members. They felt happy in knowing that they could offer some of their experiences to other family members who are struggling with the adjustments they've had to make with the residents they know in the facility:

> *I'm trying to be support to the support group at this point. I think, perhaps, this, and I don't mean this to sound arrogant but, I think because of my nursing background that, that my work experience, there's a lot that comes up there that doesn't really interest me or that, I don't need that but I figure if I go, maybe at some point, I can contribute something to the other people around the table. (Mable, Family Member, p. 27-28)*

This participant acknowledged the importance of providing support to struggling family members and was more than willing to attend the support group. Regardless of her prior work experience and knowledge, she still felt that attending would be beneficial if not entirely for herself but for the other family members who were really having a hard time. Family members who did not have health care backgrounds seemed to be more appreciative of the support group but continued to cite outside sources of support as being their more sought out forms of support. Predominately, families and friends appeared to play a large role in participants lives in terms of support. One participant went as far to say that simply being grateful for what good things she did have was a form of support on its own. She reflected on how dealing with this illness personally teaches a person a lot and being in an environment where several people have dementia makes one more appreciative of the little things. Her statement's reflected a sort of, "It could always be worse, so appreciate what you have" mentality that served as its own source of support. She commented:

> *I'm pretty strong… I had my moments but for the most part, I was able to deal with it and… just because of the fact that I accepted it and I had a very good relationship with our family doctor, and who gave me a lot of support too. I go to the support group here and I sit on that council and I, you know what? I think that being in an environment such as this facility is, with all the different types of[sighs] illnesses that the different people and that have, and what the challenges that a lot of them are facing, that I am very, very fortunate and I think that what I think that I should be able to handle what I have… I took on marriage for better or worse and yeah, sometimes it's been rough health wise with the issues and that, but nothing that I felt*

> *that I couldn't deal with and you know, continue to… I've got good neighbours, good support. I've got, as I say, a family large family. (Julie, Family Member, p. 23-24)*

Others believed that they didn't need further opportunities for education because they had already been through a process of, "learning as they went" over the years:

> *I think because we are so close, Harold and I, like we've been married for 53 years and we've always done everything together, so you just kind of learn on your own because my mother in law had, Harold's mom, had Alzheimers and, she was different all together from what Harold is so, I think each person has their own kind of identity in that respect. (Dorothy, Family Member, p. 15)*

Families seemed to understand the concept of individualism amongst different residents or individuals with dementia and realized that not everyone who acquires the disease will behave or progress through the disease in the same way. Caring for their family member prior to them being admitted forced them to learn about the disease on their own. It also, as one participant mentioned, forced them to seek out some resources such as the Alzheimer's Society earlier on. Regardless, the support that was offered upon admission to families was well received and family members made point to highlight the good job that staff did in providing them with resources right away:

> *There is a family support group which was made very clear to me when, right from the very beginning and very felt, made to feel very welcome... That was very, very clear that, that was available. There was good information given in hand outs at the time of admission. I think a lot of the rest , I mean if you're, if you're a person like me… you're dealing over the years, with a family member with dementia, if you don't know about things like the Alzheimer's Society then I don't know where you've been. You know? How can you not know? Everybody knows. (Mable, Family Member, p. 25-26)*

Families felt that it was their responsibility to be informed about some of those resources earlier on. In most cases, they had been providing some form of care to the resident at one point or another prior to admission. Participants felt that certain resources were made available earlier on and did not expect more from the facility. This theme of self support and learning on one's own carried across most of the family participants. It wasn't that they didn't appreciate what was being offered. In fact, many still attended the support group being made available to them. It's just that, for some, they felt content in seeking out their own opportunities and taking education into their own hands:

> *Any papers I find, I will… send to my children and my sister because she's the one that has no medical… awareness and sometimes, I can't send them to her either because she needs to be talked to one-to-one because she just doesn't understand things but I don't think there's really anything further; education, that I would need at this point. (Beth, Family Member, p. 18)*
>
> *Anything that's on the news, Facebook… I look into. Medication I look into… everything. I try and keep up with what's going on… I think education is always ongoing. You know, you have to keep learning… Yeah, I would definitely like to learn more or if anything changes, or if there's a new way of doing something but I just, I find for the most part, when you approach someone with Alzheimer's all you really need at first is a smile for them and they just seem to… accept you a lot easier. (Cathy, Family Member, p. 11, 14)*

So, families appear to take education in their own hands before and during admission. Whether it be through the use of the internet or through outside sources of support of their own, they are often already exposed to the disease for several years prior to admission and become forced to learn as they go. Perhaps this forced learning is due to the lack of awareness about the disease in the general population . If dementia was more frequently talked about and publicized more people may be able to seek out resources earlier than later. Other family members explained that instead of seeking out education for themselves, they focused their time on caring for their family member in care. This resulted in a similar process of learning over time without anything formal being introduced:

> *I think that there's opportunity out there if you want to seek it but I didn't, I didn't choose to seek, to go looking for it. Um, I come from a fairly large family. You know, they were supportive to me... I don't know if I would have accepted, you know, been accept… I didn't accept the Alzheimer's Society you know, inviting me to go out to their meetings and what have you. They were there but at the time Marvin was still at home and that's probably the time when help would have been beneficial to me but that was my choice that I didn't go so I can't. I can't put the responsibility on them [the facility]. (Julie, Family Member, p. 22-23)*
>
> *In the discussions that take place in that support group tend to be focused on now and um, and that's okay. A lot of us who, our hardest times were probably past; happened before the family member was admitted. That was a bad time for, for most people. (Mable, Family Member, p. 28)*

It became clear quite quickly that family members, unlike staff were forced into learning far before admission. This is because unlike staff, family members do not choose to be placed in this situation for caring for someone with dementia but rather, the situation becomes placed on them. Family members were asked specifically what types of education they would find most helpful now. At this point in their lives, having already been through a tremendous deal with their family members before admission, most felt the same way. Family members of this study felt strongly about appreciating the support given through the facility. They also felt strongly about not expecting the facility to give them support through education but appreciated the accessibility of it all. For the majority, participants answered similarly as has been outlined above. One family member did suggest that it might be useful for not just families, but every individual to become more familiar with dementia itself and how the disease really affects the individual who has it. She stressed the need to further understand what is going on in an individual's head who is living with dementia. By doing this, she believed that future attempts at improving education on understanding and dignity could be made for staff and families in the community:

> *It's not only about training. It's helping us all as family members and staff working with people with dementia. It's hard for everyone to get their head around the whole thing and to understand all the various facets of the illness and what causes people to behave the way; residents to behave the way they do. Why do they strike out? Why do they scream? To get our heads around that is more than training. It's all, I think a long term process about how, what's happening to this person? First of all, what are they experiencing? And, you can't teach that in thirty five minutes or one hour. You need to… that needs to be something we come to understand through, yes, through training or through education, through information, through experience, and so on. And empathy, whatever. But, if we don't understand… how… what's happening in someone's head whose in late stage dementia then how can we possibly… know what, how, how we should behave? We can, it's easy to wash someone's bum. That's not hard to do but that is so much, just a little piece of the whole thing. (Mable, Family Member, p. 10-11)*

Education needs to be developed in such a way that allows for an adequate amount of time to understand concepts that can be later put into practice. It also needs to involve developing techniques that will allow participants to leave with a better grasp on the disease. It may be useful to introduce some form of stimulus training into education for staff and families. For example, developing a virtual reality stimulus that replicates some of the symptoms residents experience that would allow families and staff to experience a part of these individual's realities. Furthermore, dementia awareness has only come into the forefront in recent years and so the development of better education and training programs is relatively newer in itself. Alas, family members in this study suggested that working more to understand the disease itself would be the most beneficial next step for themselves and for the general population. This awareness and understanding needs to be brought to the forefront and people need to start becoming more informed about dementia first and foremost.

Family Members Key Theme #2: Staffing

Family members involved in the study were generally pleased with the educational opportunities that the facility makes available to them. Once the conversation shifted towards staff however, family members raised some concerns about staffing on the dementia care units. At one point or another in the interviews, family participants voiced their opinions about the current staffing situation on the units filled with residents with higher needs resulting from their dementia. They understand the high demands on staff and felt that staff are often rushed in their care. In particular, families noted that when behaviours on the units were higher, staff appeared to be having more trouble keeping up with the workload. It was visibly noticeable to family members that staff were pressed for time:

> *There's not enough staff, especially for complex needs. They can only do so much and there's just, there's not enough of them… to have proper care, proper hygiene, proper feeding, changing. The, the staff ratio to patient ratio is very, very poor. (Cathy, Family Member, p. 4)*

Family members expressed their concern for staff by saying that they appear to be having trouble keeping up some days. Although generally satisfied with the care their family members were receiving, they didn't feel it was fair for staff to manage the heavier workload with the current staffing model. This raised concerns about resident safety. For example, one family member mentioned the lack of supervision on the floor at times and mentioned having witnessed falls herself:

> *They're rushed to, to, to get to… If something happens. You know somebody fell the other day. They were just standing up and they fell and they never had a problem-issues with it before but it happened to be right across from Marvin's room and I saw and you know? It just, but like, I mean, there were about five staff there… zap! (Julie, Family Member, p. 9)*

Staff cannot be everywhere at once but there are a lot of falls that happen on dementia care units that could be prevented with more adequate supervision. For example, when staff members are on break and there are no replacement staff to fill in, the chance of falls and resident aggression towards one another increases since no one is around to keep an eye on everyone and to prevent those aggressive outbursts. This was an issue of concern for families who wanted to feel that their family member was safe on the unit. They suggested that relief for those on breaks is an important issue that needs to be addressed:

> *Just watching them, I mean you get one… Aide on the floor and one nurse… and that's it because the other one's gone for break… and you need your breaks, I understand that, but maybe have somebody come in and fill in while the one goes on the break… You know, it, it's, two on the floor isn't good enough because some of them get into arguments. (Dorothy, Family Member, p. 26)*

It is important to maintain a level of staff that can adequately supervise a behavioural unit while still allowing for staff members to get their breaks. Unfortunately, replacing these staff briefly means taking staff away from other units with residents who need care and that isn't fair to interrupt their care either. This is an area that requires some brainstorming because there are a lot of barriers to increasing staffing or finding replacement staff. To begin, it would be beneficial to ensure that one staff member is never left alone on a unit where there are complex needs and that facilities frequently explore budgeting options and look into how they can maximize their staffing allowances to allow for the most coverage possible on a unit. Family members want to feel they are leaving the residents in a safe environment and felt that a lot of their safety concerns could be alleviated slightly if they knew more staff were available to provide care:

> *It's frustrating. It's just, I, I want to feel… that my dad is safe when I leave here and a lot of times, I don't feel that. It is. You think about it all the time and I, I actually have*

> *to push it out of my mind. I'm sure there's worse places he could be. (Cathy, Family Member, p. 23)*

Families should not have to feel this level of concern and so looking into staffing issues is imperative. Amongst their safety and staffing concerns, family members also raised some concerns for staff well being. In their interviews, several references were made to how tired the staff often look or how rushed they sometimes appear. Families are concerned about staff and want them to have a more optimal working environment and all the resources they need to preform their job in a more satisfying and less stressful way. It is not unusual for families to provide care while their family member is living in care. They notice the demand from staff and feel that if they can help, they will:

> *Well I think some of them get stressed out, it's only natural… And I mean, it's not just me because I'm older… They are stressed out… and I mean as long as I'm there and I can help out, I do but like if there's just one toileting somebody and somebody else wants something it's, it's not right. You know, they're gonna get burnt out…Because sometimes they really look… wiped and it's just because they haven't got enough staff. They should have more… They do get burned out. I can see it! (Dorothy, Family Member p. 27-28)*

It should be noted that no family member said they felt they were expected to help. They do it because they want to but it does beg the question: Do they occasionally preform these tasks because they want to take some pressure off staff? Some family members identified staff as being part of their family so it would make sense that they'd want to help. One participant expressed her concerns about staffing and applauded the staff's ability to keep their stresses separate from care delivery:

> *I think that there could be more [staff]. I'm [sighs], it, it's really, [laughs] I, I think, but I think everybody, everywhere you go in the health system they, you know? They could use more staff. Sometimes they're pretty stressed, the girls and that but I've never seen them take it out… on the patients. They can be stressful within themselves*

> *but not… they don't show it to the patients. Maybe because I'm here every day I see it more. I've got to know them as part of my family and ah… yeah [laughs]. So, hey, they could always improve with more [staff] but I think that they've done everything I could ask for to, to assist Marvin. (Julie, Family Member, p. 5-6)*

Most visibly noticeable to family, was the decrease in staff in the evenings and on the weekends. On the weekends, there are a lot less staff present because activities coordinators, Clinical Resource Nurses, Social Workers, and other office staff are not present. In the evenings, there are also decreases in the amount of staff when these individuals leave and because the nursing staff ratios tend to go down as well. Family members feel that this can be problematic from a safety standpoint since there are fewer eyes on the floor. They also have concerns about over-worked staff who must meet the demands of the same workload with fewer people around:

> *Sometimes on the weekends, there could be more. Because, the… [sighs] well, I don't know what… not the nurse, but the aides, I guess you'd call them… They're just going bananas… Like, today they were… being as hard as my husband, I can do things so I washed him up and I changed him, and got him dressed and the whole bit. Just, to kind of take the pressure [abruptly and sternly] I don't have to, nobody's ever asked me. It's just… I'm here. I'm just sitting, so. (Dorothy, Family Member, p. 6)*

When staff are busy or fewer staff are present, families suffer. For example, one family member finds it frustrating when she comes to visit in the evenings because she is often unable to find any staff. During these times, Health Care Aides are likely in the midst of preforming care and are therefore unaccessible to the family member at that time. So, unfortunately, if a family member does have a question or concern, they have to wait until one of the workers does have an available moment. There was also some concern about care quality and the implications not having enough accessible staff has on the quality of care that residents can be expected to receive. One participant commented:

> *In regards to gaps in care: Lack of hygiene. Like to come and, and I've.. most times I come, I have to… wash my father's face, wash his hands, because their filthy, his face is filthy. Dry skin. Stuff like that... It's hard leaving. It's hard coming and, and seeing him dirty or not changed or you know, sitting in urine or feces, it's, it's… tough. (Cathy, Family Member, p. 16, 24)*

Another pointed out that sometimes the amount of equipment for staff itself, interrupts care:

> *I think there's like twenty-six beds there, I think and I think there's one lift and there's several people. Well, if my husband decides he has to go to the washroom then they have to run down to the other end of the hall to get that lift and then they have to come back so some… sometimes it's the lack of equipment not the lack of equipment but the lack of the, lack of the… enough equipment. (Dorothy, Family Member, p. 9)*

It should be noted that despite these concerns, family members across the board still applauded the staff who were on the units more frequently. Families believed that staff are doing the best they can with what they have and families were particularly happy about the calm demeanour and approach staff took with residents on the units:

> *They've never talked harshly or anything to the patients… You know I mean, I guess there are times that they could, but they never do. They never do.. and a lot of times they don't even know that I'm there. So they're not putting on a show or anything, its, this is how they are. (Dorothy, Family Member, p. 9-10)*

Family members felt that even though staff may be rushed at times, they still take the time to provide the best care they can with the resources they have. Families feel supported and like that the staff in this facility are approachable and kind when issues or concerns are brought to their attention. Despite being staffed at what many deem to be an insufficient level, staff try their best to provide good care and to accommodate and include families. One commented:

> *I think I'm a patient person but I'd be pulling my hair out and I admire the people. They never lose their cool with her and they always seem to understand and it's not just one, it's so many of them… They're patient, they're approachable. They don't seem to get angry with the people. (Julie, Family Member, p. 16)*

Like staff, family members identified the issue of staffing and how it can have a negative effect on the provision of care. They also saw how staff members thrived under more stressful situations. This is an example of how education and training on dementia and approaches can be positive. Staffing has been an issue for some time and will likely continue to be an issue for long term care. If the staffing levels are not going to increase, then the amount of education and training for staff needs to. Staff need to be better prepared for working in this type of environment. Through education and more efficient and regular training, staff will presumably be able to fair better in providing care under more stressful and busy situations.

Family Members Key Theme #3: Personhood and Engagement

Person centered care has been mentioned several times in this document and that is because it is a major cornerstone to effective and applaudable dementia care provision. When staff are well trained and educated about dementia, they are more likely to exhibit traits that mirror a person-centered care approach. Family members in this study recognized some of the struggles direct care staff go through on a daily basis and applauded them for the care their families received in the facility. Despite the many struggles associated with working in a high demand environment like this, family notices staff taking the time to remain engaged as much as possible and to demonstrate a noble effort to provide person centered care. Below, are a few of the many kind words family members spoke about the staff in this facility that reflect a delivery of person centered care:

> *They're very kind, and they talk to him like he's a level. They don't talk down to him and I don't think they do with any of them. They talk to them as they are an equal, and that kind of helps too… Because I sometimes help with his bath if he's really irritated and if I'm around he won't, maybe take somebody out, [laughs] but um, ah,*

> *but no. They talk to him just like he's an equal and I think that's good… They're very kind to him. (Dorothy, Family Member, p. 23).*
>
> *I think that they're all… overly busy but they still take time for the, you know, for the patients and the… you know, and I think that's reflected as a chain reacted through the staff… Uh, as you can tell [both laugh] I am an advocate for the staff because I really and truly and sincerely, I do feel that way about it. (Julie, Family Member, p. 26-27).*
>
> *They will sit down with the resident… and just talk to them or try to talk to them. 'Cause I know people… like with my husband, he talks with no purpose…That's how far gone he is, that he will just jabber on but it just doesn't make any sense and every once in a while he will come out with a nice blurb and they will comment that, "Oh he's got real character, he must have been, what a character." But, they take the time to… try to know the resident and they seem to know them all very well and the families as well. (Beth, Family Member, p. 7)*

It is clear from these statements that these family members have had positive experiences with staff in this facility and that they appreciate the care being provided. Presumably, the education and training staff have received thus far has played some role in achieving a framework for delivering person centered care to the residents. Despite the high demands of delivering care to multiple people, staff still take the time to individualize care and to establish a rapport with residents and families. Family members feel included in this facility because staff take the time to make them feel included. One family member noted exclaimed:

> *I've been thrilled, as, now, I am taking specifically about this facility and the unit because I'm seeing this as a wife. I am thrilled to see how the staff after getting to know my husband and of course and you see, I see that with other residents too. It's lovely when they are walking down-if I'm wheeling him down the corridor and they're coming towards us, when they say hello to him. You know? They don't, they have no reason to do that right then and there. They're working; probably, they might be carrying a handful of dirty laundry or whatever and have their mind on, on something else that they're doing right now but when they uh, they take that second just to say hi, and call my husband by name and smile at him, or stop for a second and say hello, or stick their head in, even into the room to say to me or to both of us. I think that's really lovely and that tells me that they have, that they accept him as you know, part of the… I mean that's just part of the, their… as part of their*

> *environment and, and they see it, and they, and they take the time to do those things. I think that's great. (Mable, Family Member, p. 24-25)*

The staff members' concerns appear to extend beyond just preforming care and including the residents. In the family members of this study's experiences, the staff care for the residents' whole families and take a vested interest in building friendships. This type of rapport is a real strength in care provision because it gives the residents a sense of home and families a sense of security, knowing their family members are being looked after by staff who treat them as the individuals they are. It is imperative to continue to stress the importance of personalized care and to promote the inclusion of families in the care of residents.

Conclusion

Talking with staff and family members provided a breadth of information about what strengths and gaps were present in the dementia education and training provided in this facility. In terms of availability, it appears that although staff are happy with what's being offered when it is being offered, they would benefit from having courses more widely available to them. Courses on dementia appear to be limited and are not offered as frequently as would be beneficial to staff. Because of this, the facility finds that there is a slight stagnation in educated workers. For example, some staff have received P.I.E.C.E.S training while others have not. In order to be able to facilitate the P.I.E.C.E.S framework effectively, everyone needs to be on the same page. Other courses that focus on resident and staff safety have become less frequently offered as well, making it hard for willing staff members to attend.

Family members felt supported and felt that the facility does its best to offer them what becomes available or what is available in terms of their own education. They were positive about the support group and for the most part, felt that the facility was not responsible for providing them with any more education. They were aware about what was available and were appreciative. Across the board, most family members felt that it would have been more helpful for them to receive these types of supports earlier on, when they were first beginning to go through the transition of their family member acquiring and living with the disease. Up to this point, most of them had learnt as they went and felt pretty content in where they were now. One suggestion was made in terms of what would be helpful in the future for every person and that was establishing more understanding about the person with dementia. Specifically, looking into some of the causes and identifying what exactly is going on in that person's head. Exploring why they may strike out or do and say certain things was thought to be an important next step.

Staff were pleased with the hands on training they have received and the content of the education they've taken part in in this facility. Specifically, most had positive things to say about the P.I.E.C.E.S course because it helped them to identify better ways to provide care to individuals with dementia. They appreciated that the course was designed specifically for this population and only had minor content concerns. Firstly, participants believe that a formal design of P.I.E.C.E.S for Health Care Aides would be beneficial. Secondly, incorporating more information on medications was suggested. In terms of other content issues, staff believed that it would be helpful to receive more injury prevention and non-violent crisis training, as well as some more education on caring for individuals with dementia in the end stages of life when they become palliative.

Many safety measures were mentioned that have been put in place for staff and resident protection. These include: panic buttons for staff members to use in situations where they feel they are in danger or at risk for injury with residents, the Blue Dot Program for more difficult residents, the implementation of a hallway monitor on some units to prevent resident falls and fights, and regular meetings with staff to assess any issues on units involving safety concerns. Staff feel that the facility is doing its best to make safety a priority but most participants felt more work needs to be done in order to further improve safety for all. Staffing or rather, the need for staffing was identified as a major safety concern. Participants often felt that staff are placed in a dangerous work environment when there aren't enough hands on the floor. This is because when care is being provided, there are often un-monitored residents. Family members identified this as an area of concern as well and felt that in order to provide better safety for all, the staffing issue needs to be addressed. Staff also suggested that it would be beneficial to continue efforts on training measures or education that would help them manage more aggressive residents better.

The staff in the facility recognize the importance of person centered care and do their best to provide it to their residents. Although most of this learning has been done hands on and over time, they've appreciated the P.I.E.C.E.S course because it has helped them further develop their skills in approach and dealing with residents who become more resistive to care. P.I.E.C.E.S aids staff by equipping them with some helpful tools to continue managing these residents more effectively and appropriately. Family members applaud staff as well because they notice the person centered care being done despite what appears to be, very busy and very rushed staff. Despite the busy nature of behavioural units and a heavy workload, staff in this facility make families and residents feel included. They engage in conversations that reflect the personhood of the residents and try their best to remain as engaged as possible. Staff also engage the families themselves and make them to feel included. Even so, all participants recognized that there are still barriers to providing personalized care sometimes. When staff are rushed and/or understaffed and residents are more resistive or if a resident becomes aggressive, staff do not necessarily always have the time to give each resident as much attention and engagement as they would like to. This is an area that requires some focus since staff engagement with residents is an important factor to delivering good person centered care.

The next chapter will provide a discussion of the findings. It will include four sections: Suggestions for Future Directions and Research, Research Implications, Limitations of the Study, and Conclusions.

CHAPTER FOUR: DISCUSSION OF THE FINDINGS

The purpose of this study was to provide an introductory look into the current dementia education and training for staff in long term care who work with individuals living with dementia in long term care. This was done through a qualitative approach that examined the thoughts and beliefs of family members of individuals living with dementia, as well as staff members who provide direct care to individuals with dementia in long term care. Specific objectives included identifying the strengths and gaps of dementia education and training that is currently present in one setting. This was done by identifying themes present in the responses of participants with the intention to apply their thoughts to what can be done to improve the provision of education and training in long term care in the future.

Dementia has profound effects on residents who have it which makes identifying strengths and gaps in the provision of education and training extremely important. In order to produce quality care, the delivery of care needs to be high quality in itself. When there are staff who are undereducated and undertrained working with a vulnerable population, the chances of complications in providing care may increase. This increases the need for a well put together formal education and training regime. Residents who display more escalatory and complicated behaviours can be challenging at times for staff who want to deliver a high standard of care. It is also important to consider the role of ageism and how it effects the delivery of care to residents living with dementia in long term care facilities. Sometimes staff can be too preoccupied in their tasks to involve residents on a personal level. This is a major barrier to care since it has been shown that person centered care and meaningful communication is essential for good dementia care (Kitwood, 2007). Without a good foundation to learn from, staff enter these environments without the tools they need for success in working with this population. In particular, staff who are not introduced to core concepts of person centered care and how to approach residents will be more likely to display ageist behaviours whether they be intentional or not. For example, staff may not understand that a resident who is acting out or rambling is trying to communicate a need; that there is more to their behaviour than just the disease. Understanding dementia and the challenges associated with the disease is important for staff in long term care. Learning how to identify any unintentional or underlying ageism will produce better care results and lower the rates that these residents are de-humanzied by promoting understanding about the disease. There is a risk for residents to be looked after by people who may uphold ageist beliefs or attitudes or by those who display ageist behaviours unintentionally because of a lack of understanding. This is concerning because these actions will lead to the delivery of substandard, low quality care and poorer quality of life for residents (Irvine et al., 2012). Thus, it is extremely important for staff in long term care settings to receive proper and recurring education and training aimed at appropriately providing care to older adults living with dementia.

This chapter begins with a section on suggestions for future directions and research.. This is followed by the implications of the research. The third section outlines the limitations of the research.The final section concludes this thesis with a brief summary.

Suggestions for Future Directions and Research

Improving the provision of education and training for staff and families is crucial in order to provide maximum benefit to the staff, residents, and family members. In many ways, dementia education and training for staff and family members is strong. In fact, it appears that there’s been growing trend to pay more attention to education on dementia because of the growing prevalence of dementia in the population. Many staff participants commented on how the opportunities for education and training have grown since they first went to school or began working. This is a good indication that it will continue to grow as the issue of under-educated and trained staff is more widely recognized. Staff need to feel comfortable and safe when they are providing care to more resistive or aggressive residents. By giving them the proper tools to work (education and training), staff will be better able to provide a higher quality of care to their residents while feeling more comfortable doing it. Furthermore, families who are more educated helps to reduce some of the stress they experience and allows them to communicate better with family members because they have a deeper understanding of the disease.

Despite the advancements and growing recognition of dementia's prevalence in the population, there are many areas in education and training for staff and families that require attention and improvement. Firstly, there were several issues with availability of education and training for staff members. In particular, there was concern about the frequency of education being provided, the barriers that get in the way of receiving education and training, the lack of continuing educational opportunities, and the lack of solid program availability. Education is often held back because of a lack of regional educators or professionals with the credentials to teach them. It may be helpful to address this by having more priority paid to the dwindling number of qualified professionals and seeking out those who would be interested in teaching. This could be done by placing information about how to become a regional educator throughout facilities. Other programs cost money and with an allowance of only so much for education, facilities need to look into what education is best suited for their direct care staff who work with individuals with dementia and prioritize accordingly. P.I.E.C.E.S was identified as being rather useful but even it has availability issues associated with it. Strategies to make this program more frequently available are needed so that all staff can be educated rather than just a few. The creators of P.I.E.C.E.S may also find it useful to adapt the current program to include a formal training for Health Care Aides that includes information on medications. It would also be beneficial to address the need for continuing education. Many participants suggested a refresher course or small refreshers on different topics. Since the more important issue is getting staff trained in the first place, perhaps there are ways for the facility in this study to implement periodic refreshing sessions in their yearly education days and provide similar refreshers in other facilities. Family members were less worried about availability of education for themselves since they felt that they were provided everything they needed. A suggestion for all facilities would be continuing to offer that support system and to make sure that families are always aware of their options to receive education on dementia. The Alzheimer's Society might also find it useful to incorporate education for the families in contact with them. Specifically, education on the different types of dementia and how they may affect an individual's behaviour is needed. Moreover, information on death and dying and how to cope with those end stages of life and how to communicate with their families in those times is an important missing piece. Frequently, the family members in this study mentioned that they don't expect the facility to provide them with education. Regardless, its crucial to continue providing families with accessible opportunities for support and education because they can equally benefit from receiving them.

In terms of content of the courses currently offered, it may be useful to create a program that incorporates all of the problem areas identified by staff in this study, all in one. That is, having something like P.I.E.C.E.S that breaks down the different types of dementias and approaches and medications but that also incorporates a section on injury prevention techniques as well as a section about death and dying and palliative care for individuals with dementia. This would eliminate the need for several programs to be offered and reduce the overall costs associated with education because facilities would be having to send less staff to fewer things. There were also lots of comments about having few options for dementia specific education aside from P.I.E.C.E.S and so, compiling all of those programs into one and focusing on them as they pertain to dementia care would be very beneficial. Furthermore, by having staff receive a well rounded education that not only teaches them about the disease but also about how to remain safe and understanding of residents who are in the end stages, will increase care quality and the quality of life of the residents. Families deserve to have a better understanding of the disease and so, if facilities do offer support groups like this one, it is important to provide them with information similar to what staff receive about approach and understanding.

Safety needs to be made a priority and so future education needs to prioritize not only resident safety, but staff and family safety as well. Staff need to be given the tools to protect themselves and the residents and they need to feel safe in the workplace. It may also be useful to aim future research at what escalates or deescalates behaviours and aggression and incorporate that into training for staff and families. As well, facilities need to be ever looking into ways to keep everyone safe and so measures like the panic button or Blue Dot Program are a step in the right direction. Staff may also find it beneficial to have communication device such as a headset to be able to communicate with others on the unit when a call bell is not accessible to they may be unable to push a panic button. Furthermore, with staffing being such a huge issue in terms of supervision and safety concerns, budgeting for staffing needs to be prioritized. If one to ones and hallway monitors have been shown to be effective in reducing falls and aggression among residents and staff, then perhaps the benefits of having more staff need to be studied further.

There is also a need to address how to better implement and promote person-centered care among staff in an environment with such a heavy workload at times. This may be done by continually reminding them how to best engage residents and to encourage them to remember that these older adults are still people who had lives. They had interests, hobbies, and families and deserve to be treated with dignity and respect. Too often people with dementia are categorized by their disease because there is a lack of knowledge among staff about the disease itself. Training workshops need to be developed to teach staff about the kinds of dementia and how to engage individuals more effectively. Acknowledging the person and not the disease is paramount to older adults receiving better care in long term care settings. If there is no reduction in age discrimination against older adults there is an overwhelming possibility that the provision of care will continue to suffer amongst future generations. Families also feel more at ease when they know that their family member is being treated more personally and the residents experience greater quality of life. Future research needs to continue to look into ways of increasing person centered care where staff experience barriers to giving it. It may also be useful for P.I.E.C.E.S to develop a section where they teach staff how to actually implement the care they describe in the programs as it is one thing to teach the comments and another thing to use them in practise.

Lastly, the curriculum of both Nursing and Health Care Aide courses need to be reviewed and assessed. The lack of dementia specific content is very concerning given the growing rate of people in the population who are anticipated to have some form of dementia in the coming years.

Even though not every Nurse or Aide will end up in dementia care or even long term care, dementia content is important. Long term care is not the only place people live with dementia. It is in the community and hospitals and quite frankly, nearly any health care setting you can think of. This significantly increases the chances of health care professionals having to take care of individuals with dementia. It may not be in a long term care home and it may not be the case that every resident they are caring for has it but it is likely that at some point these professionals will encounter someone living with dementia and they need to be prepared to deliver the same quality of care to them as anyone else. Further to that, it is irresponsible to have people caring for individuals with dementia before receiving any formal education or training and unacceptable to continue allowing hands on training and learning on the job to be the primary source of education. Staff and residents deserve the benefit of getting the tools they need before they are thrown into a situation where there is real potential for safety and well being issues. One final suggestion would be for a more standardized dementia education and training system across provinces and within facilities. Having too much variation in training promotes care inconsistency and too many differences in provision across facilities from region to region. It is important that all facilities be on the same page so that the quality of care can continue to grow and the well being of staff, family members, and residents can continue to increase.

Research Implications

The implications of this research are vast. To begin at the heart of why it was first proposed, this research has the potential to help direct care staff members and families immensely. By identifying what staff and family members perceive as strengths and gaps, one creates a starting point for future advancements. Areas of education and training that appear strong and helpful can be strengthened while areas deemed as lacking or in need of improvement can be assessed. The more developments that are made to provide better training for staff and education and training for staff and family members will yield more positive results for both. Staff will feel more comfortable and confident in the workplace, become less stressed, feel more supported, and therefore, provide better care. Family members who are more educated may experience a better transition through the process of their family members disease advancement and admission into the facility. They will also benefit from understanding why individuals with dementia behave the way they do sometimes and be better able to communicate with their family members. Lastly, the residents themselves benefit tremendously from staff and family members being educated on dementia. By continuing with this research and building on further to it to improve dementia education and training, residents will receive higher quality, more personalized care. Those caring for them will be better able to suit their needs and therefore, contribute to a higher quality, less stressful life for residents. On a broader level, this research has the potential to effect non-health care professionals by drawing attention to the larger need to educate the population as a whole. Dementia has come into the forefront as one of the largest causes of disabilities in old age and with the ever growing number of individuals acquiring the disease, it will become very important to take care of some of these issues in education and training now so that long term care can become better suited for this growing problem.

I intend on providing a summary of the findings of this thesis to the facility and participants that took part in the research study, as well as to a few individuals I know personally who are involved in providing education for staff and families. It is my intention to approach individuals involved in long term care to discuss these findings of this study in the hopes that it may get the ball rolling on discussing some of the safety concerns brought up by staff and families as well as some of the educational concerns. Furthermore, I plan on discussing the findings of this study with a regional educator who has contacted me and who works directly with the P.I.E.C.E.S program so that this information does not become lost with this written thesis. The dissemination of these findings are an important piece of this research as I believe this study is only a starting point for continuing to address the growing need to develop different areas of dementia care within Canada.

Limitations of the Study

Though successful in many was, this study was limited by a couple of things. To begin, the original intention was to have at least two long term care facilities take place so that findings would be more generalizable and transferable between facilities. Since only one facility took part, one can only make assumptions or hypothesis about whether or not the findings from this study can be applied to other long term care facilities or if they are exclusive to this one. That being said, the researcher still believes that this research was rich and that the experiences of people in similar situations would yield similar results. A second limitation of the research was that for direct care staff, only Health Care Aides were recruited while the hope was to receive a combination of RNs, RPNs, LPNs, and Aides. With this being the case, the majority of the focus was shifted to education and training for Health Care Aides in long term dementia care. Still, the managerial staff and Clinical Resource Nurses were helpful when discussing the overall dynamics of workers on these units and the researcher believes that many of the suggestions for future directions will benefit all direct care staff. Lastly, the majority of staff members in this study had been working in their positions for a fair number of years. This may have shaped the findings slightly since replicating the same study with newer and less experienced workers may have yielded different results. Despite these limitations, the study was still very exhaustive and provided great insight on the subject matter.

Conclusions

The intention of this chapter was to provide a discussion of the findings while considering their implications for future research and possible limitations. The suggestions for future directions and research are vast and include: looking into how programs can be made available more frequently and on a continuing basis, adapting current education and training to involve more on understanding dementia and approach, injury prevention techniques, death and dying, and exploring what can be done to encourage the continuation of person centered care in a limited staff environment. The implications of this research focused on what strengths and gaps were currently present in the provision of dementia education and training for long term care staff and family members. The intention was to identify where the provision of education and training could be improved to provide maximum benefit to the staff, residents, and family members. Though limited in some ways, this research study was exploratory in nature and aimed to provide an introductory look into a large issue. Despite the limitations discussed previously involving recruitment issues, this study accomplished the original goals and exceeded the expectations of the researcher. The study succeeded in shedding light on the need for continual improvements to be made in the current provision of dementia education and training for long term care staff and addressed some areas that can be used as a starting point to improve that provision. Residents living with dementia deserve to have well educated and trained staff providing their care and staff deserve to feel comfortable in their work. Dementia prevalence in the Canadian population is growing and individuals living with dementia in long term care is also increasing. Thus, it is important to continue looking into ways to better the provision of education and training for staff who work in these environments in order to provide maximum benefit to the staff, the residents, and the family members who are affected.

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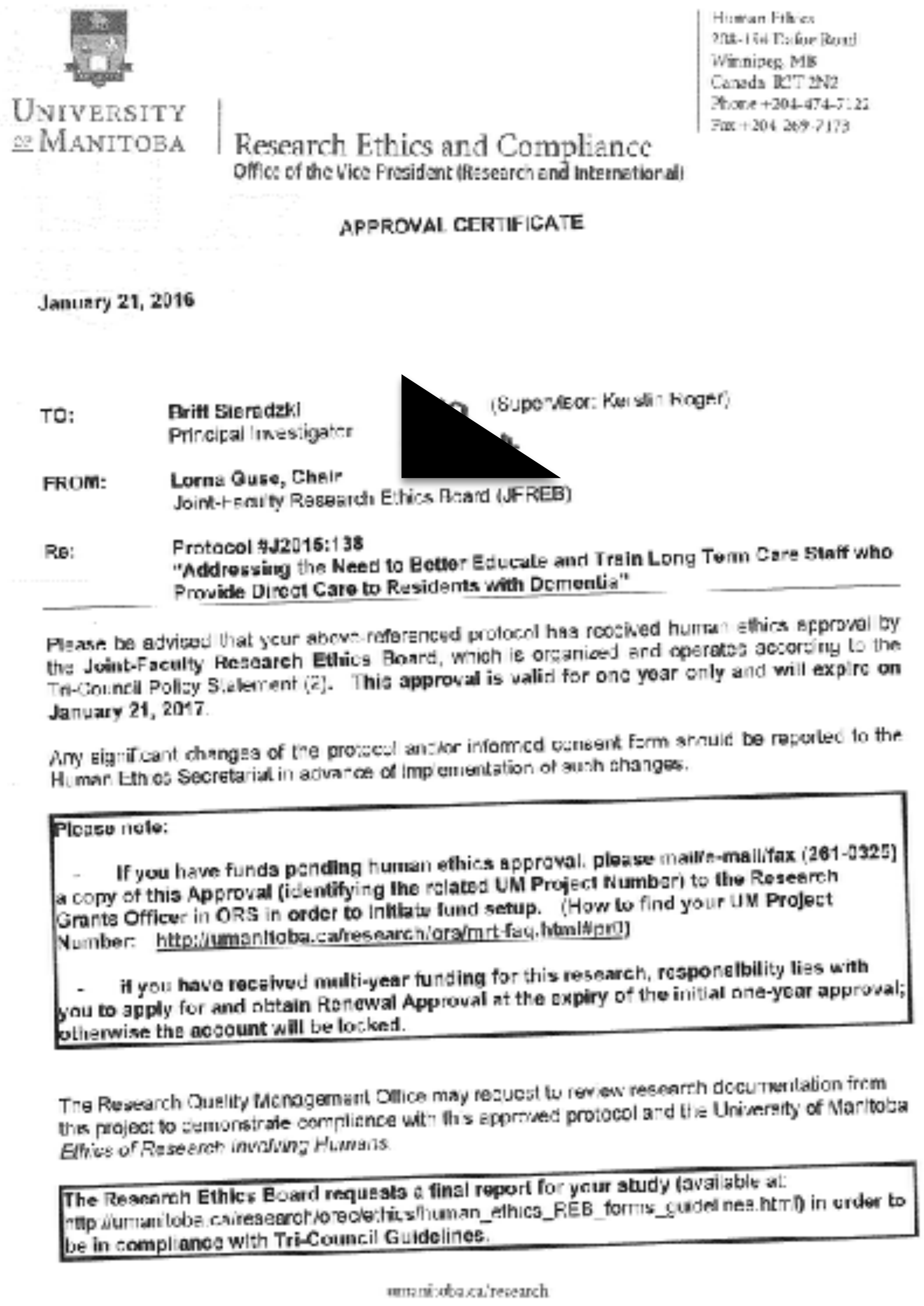
Appendix A: Joint Faculty Ethics Board Approval Certificate



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APPROVAL CERTIFICATE

January 21, 2016

TO: **Britt Sieradzki** [redacted] (Supervisor: Kerstin Roger)
Principal Investigator

FROM: **Lorna Guse, Chair**
Joint-Faculty Research Ethics Board (JFREB)

Re: **Protocol #J2016:138**
"Addressing the **Need to Better** Educate **and Train Long Term Care Staff who Provide Direct Care to Residents with Dementia"**

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics** Board, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only and will expire on January 21, 2017.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- **If you have funds pending** human **ethics** approval, **please** mail/**e-mail/fax** (261-0325) a copy of **this Approval (identifying the related UM Project Number)** to **the Research Grants Officer** in **ORS** in **order to initiate fund setup.** (**How to find your** UM **Project** Number: http://umanitoba.ca/research/ors/mrt-faq.html#pr0)

- **If you have received multi-year funding** for **this research, responsibility lies with you to apply** for **and** obtain **Renewal Approval at the expiry of the** initial **one-year approval; otherwise the account will** be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research involving Humans*.

The Research Ethics Board requests a **final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.**

umanitoba.ca/research

Appendix B. Recruitment Poster Example

THE UNIVERSITY OF MANITOBA

Community Health Sciences/Family Social Sciences
Winnipeg, Manitoba
Canada, R3T 2N2

RESEARCH PARTICIPANTS NEEDED

Do you work directly with individuals living with dementia in long term care or are a family member of someone living with dementia in long term care?

The purpose of this project is The purpose of this project is to examine what education and training options are available and provided to long term care staff in Winnipeg, Manitoba who work directly with individuals who have dementia. I intend to look for areas where education and training for staff may be improved. By identifying and addressing the strengths and gaps in current education and training, improvements can be made in order to achieve better care provision. I am interested in the stories and experiences of nursing staff, managers, and family members who are affected by the current care provision for individuals living with dementia in long term care.

<u>You can participate if:</u>

- You are a health care aide, personal support worker, RPN, LPN, RN, special care unit manager, family member of an individual living with dementia in long term care.
- You are willing to provide up to 1 hour of your time to be interviewed.
- You have a family member living in long term care with dementia now.

You will be given the option to review the written analysis of the study's findings. Total maximum time commitment, including review of the analysis if you choose, will not exceed 4 hours.

This study is being supervised by Dr. Kerstin Roger, Associate Professor, Faculty of Community Health Sciences.

Are you interested?
Please contact:
Britt Sieradzki, M.Sc Student (Principal Investigator)
Phone: [redacted]
Email: umsierab@myumanitoba.ca

or
Kerstin Roger, Associate Professor (Thesis Advisor)
Phone: 204-474-6354
Email: Kerstin.Roger@umanitoba.ca

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact Britt Sieradzki or Dr. Roger or the Human Ethics Coordinator at (204) 474-7122 or email: Pinar.Eskicioglu@umanitoba.ca or humanethics@umanitoba.ca.

Appendix C. Recruitment (Letter/Phone Call) Guide

Hello,

I am currently a graduate student enrolled in a Masters of Science program in the department of Family Social Sciences within the Faculty of Human Ecology at the University of Manitoba. I am conducting a study entitled: Addressing the Strengths and Gaps in Education and Training for Long Term Care Staff Who Provide Direct Care to Individuals Living With Dementia. I am interested in learning more about what current dementia education and training opportunities are available for nursing staff members in long term care facilities. As well, I wish to see where there are strengths and where there is room for improvement in the current education and training that exists.

I am looking to recruit participants for a study to inform my thesis work as well as any publications and presentations that may result using findings from the study. In order to conduct my research, I am looking to recruit two to three long term care facilities, managerial staff of locked/behavioural/dementia care units, and family members of residents who have dementia to participate in an interview via face-to-face, telephone, or Skype. It should take approximately one hour of your time.

Before the interview takes place, I will email you a consent form for you to read, consider, and sign. I will then ask that you email or fax me a copy of the signed consent form before scheduling a time to conduct the interview. If you do no have access to do this, I will ask that you arrive to the interview with a signed copy of your consent form. At that point, I will have brought a secondary consent form for you to sign so that both myself, and you have a copy of the consent form prior to the interview. I will go over this consent form again at the time of the interview at which point you will be prompted to ask any questions you may have for clarification. I will record the interviews on a digital voice recorder and later transcribe them as to ensure I do not miss any information you give me. These notes will assist me in recalling our discussion and also serve as a back-up in case the digital recording malfunctions or is inaudible in any way.

I do not anticipate that there will be any risks for you that result from choosing to participate in my study. In fact, you may find it helpful to consider how efficient education and training can benefit nursing staff, family members, and residents with dementia.This study has been approved by the Joint Faculty Research Ethics Board in conjunction with the University of Manitoba.

Your confidentiality will be maintained, as I will not refer to you by name in the disclosure of my findings. I will assign you a pseudonym. This means that I (the researcher and interviewer) will not share any information from this interview with anyone other than my thesis advisor. I will not use your real name in the disclosure of data findings. However, because I have no control over what you wish to say outside of the interview, I cannot promise you complete confidentiality should you decide to discuss your participation in the interview.

If you choose to participate in this study, you may refuse to answer any questions or end participation at any time. If you do choose to withdraw from the study at any point, any data collected from your participation will be destroyed and will not be used in the analysis of data or dissemination of the study's results.

After the research is complete, I will send you a summary of my findings.

It is anticipated that the results of this study may be used to inform my future thesis topic and be used in future presentations and publications. When study results are shared, all findings will be presented in a way that does not identify any of the participants.

The only people who will have access to the raw data (audio interviews, notes, and transcripts) will be the Principal Investigator, myself (Britt Sieradzki) and my thesis advisor. Raw data will be stored for a period of at least five years, as it is anticipated that the data may be used to inform my thesis topic and be used in presentations and publications. The researcher (myself, Britt Sieradzki) and advisor may wish to access the anonymized data collected from this study (anonymized transcriptions and findings, not raw data) again in conducting future studies. Upon the completion of my thesis, if the data is not anticipated to be used again, all raw data will be destroyed. The electronic data will be erased/wiped clean from the digital storage device. Hard copy data will be shredded. I cannot provide an exact date for destruction as the researcher anticipates that the data may aid in future study of the proposed topic but it will not be kept past May, 2020.

I am planning to hold the interviews as soon as possible upon recruiting two to three facilities. If you would like more information or if you would like to take part in an interview, please send me an email or call me. My contact information is listed below.

If at any point, you have any concerns, please feel free to contact me directly. Listed below is my contact information, at well as my advisor's, and the Human Ethics Coordinator.

Thank you,

Britt Sieradzki, Graduate Student, Department of Family Social Sciences
umsierab@myumanitoba.ca
[redacted]

Thesis Advisor:

Kerstin Roger, Professor, Faculty of Human Ecology
Kerstin.Roger@umanitoba.ca
204-474-6354

Human Ethics Coordinator:

Pinar Eskicioglu, Human Ethics Coordinator
Pinar.Eskicioglu@umanitoba.ca
(204) 474-7122

Appendix D1. Demographic Survey Questions For Staff Participants

1. What is your age?

_____18-24 years old
_____25-34 years old
_____35-44 years old
_____45-54 years old
_____55-64 years old
_____65-74 years old
_____75 years or older

2. What is your gender?
_____ Male
_____ Female
_____ Transgender
_____ Fluid
_____ Genderless
_____ Other. You may specify if you wish: _______________

3. Ethnicity origin (or Race): Please specify your ethnicity.
_____Canadian
_____English
_____French
_____Native American or North American Indian
_____Asian
_____German
_____Other. Please Specify: _______________

4. Job Title: What is your current working position?
_____Director of Care
_____Special Care/Behavioural Unit Manager
_____Registered Nurse
_____Registered Practical Nurse/Registered Licensed Nurse
_____Personal Support Worker/Health Care Aide
_____Other: Please Specify __________________

5. How long have you been working in this position?
_____ Less than 1 year
_____ 1-5 years
_____ 6-10 years
_____ 11-20 years
_____ 21-30

_____30+ years

6. Marital Status: What is your marital status?
_____Single, never married
_____Married or domestic partnership
_____Widowed
_____Divorced
_____Separated

Appendix D2. Demographic Survey Questions For Family Participants

Please Check Responses accordingly. If you are uncomfortable answering a particular question or would prefer not to respond to some, you may choose not to answer those questions.

1. What is your age?

_____18-24 years old
_____25-34 years old
_____35-44 years old
_____45-54 years old
_____55-64 years old
_____65-74 years old
_____75 years or older

2. What is your gender?
_____ Male
_____ Female
_____ Transgender
_____ Fluid
_____ Genderless
_____ Other. You may specify if you wish: _______________

3. Ethnicity origin (or Race): Please specify your ethnicity.
_____Canadian
_____English
_____French
_____Native American or North American Indian
_____Asian
_____German
_____Other. Please Specify: _______________

4. Education: What is the highest degree or level of school you have completed? If currently enrolled, highest degree received.
_____No schooling completed
_____Nursery school to 8th grade
_____Some high school
_____High school graduate, diploma or the equivalent (for example: GED)
_____Bachelor’s degree
_____Master’s degree
_____Professional degree
_____Doctorate degree
_____Other. Please Specify: _______________

5. Marital Status: What is your marital status?
_____Single, never married
_____Married or domestic partnership
_____Widowed
_____Divorced
_____Separated

6. Employment Status: Are you currently…?
_____Employed for wages
_____Self-employed
_____A student
_____Retired
_____Unable to work
_____Other. Please Specify: _______________

Appendix E. Interview Guide for Managerial Staff

Opening Comments

"Hello (participant's name). First off, I would just like to say thank you for agreeing to participate in this interview today. What we're going to be discussing, is the current education and training options that are provided and offered to nursing staff members in long term care facilities.The purpose of this project is to examine what education and training options are available and provided to long term care staff in Winnipeg, Manitoba who work directly with individuals who have dementia.

Since we have already gone over the formal consent process, we may begin the interview should you require no further clarification. That being said, is there anything you would like clarification on in regards to the consent form before we begin?

There are no right or wrong answers in this interview. In this research study, I have promised to keep the information you share with me confidential. This means that I (the researcher and interviewer) will not share any information from this interview with anyone other than my thesis advisor when using this data to inform my future thesis. I will not use your real name in the disclosure of data findings. However, because I have no control over what you wish to say outside of this interview, I cannot promise you complete confidentiality should you decide to discuss your participation in the interview.

Please remember that, I will be recording this session in order to transcribe it later as not to miss any important points discussed. For this reason, it would be helpful for you to speak as clearly as possible - I want to be sure I get down everything that you want to say.

Do you have any questions before we begin the interview?

Introductory Comments

Could you please tell me a little bit about yourself and why you chose to participate in my study?

Transition Comments

Thank you. As you know, dementia affects a person's ability to perform everyday activities and many individuals who develop this disease will require the use of formal care. According to the Alzheimer Society (2010), approximately 500,000 Canadians have dementia today and it is the most significant cause of disability among Canadians over the age of 65. Dementia costs Canadian society many billions of dollars each year and forecasts predict that there will be, "65.7 million [people] in 2030 and 115.4 million [people] in 2050" (World Alzheimer Report, 2009) that have some form of dementia. Furthermore, forecasts predict that within 20 years, the worldwide prevalence of dementia will increase two-fold (ibid). With this being the case, it's important to address the current care provision for these individuals.

Key Questions/Probes:

1. *What dementia training is currently required for your nursing staff who provide direct care to residents with dementia?*

- How many training shifts do new staff receive on locked or behavioural/dementia care units?
- Do new staff receive any dementia-specific classroom orientation sessions when they are first hired?
- What is the staffing ratio on your behavioural units?

2. *Do you provide continuing dementia education and training for your staff members?*

- As a manager of the special care unit, how to you keep staff up to date on current opportunities for dementia education and training?
- How do you assess staff readiness in working with residents with dementia? If they are having trouble providing care, are there opportunities for them to receive further training?
- Do you believe that your facility provides adequate dementia education and training for nursing staff?

3. *What are some strengths you see in the current provision of dementia training and education in your facility?*

4. *Where do you see room for improvement in the current provision of dementia training and education in your facility?*

Conclusion

We have covered a lot of ground today. Before we finish, is there anything you would like to add or change in regards to your interview responses. I want to make sure I’ve gotten everything right.

Thank you for your participation.

Appendix F. Interview Guide for Nursing Staff

Opening Comments

"Hello (participant's name). First off, I would just like to say thank you for agreeing to participate in this interview today. What we're going to be discussing, is the current education and training options that are provided and offered to nursing staff members in long term care facilities.The purpose of this project is to examine what education and training options are available and provided to long term care staff in Winnipeg, Manitoba who work directly with individuals who have dementia.

Since we have already gone over the formal consent process, we may begin the interview should you require no further clarification. That being said, is there anything you would like clarification on in regards to the consent form before we begin?

There are no right or wrong answers in this interview. In this research study, I have promised to keep the information you share with me confidential. This means that I (the researcher and interviewer) will not share any information from this interview with anyone other than my thesis advisor when using this data to inform my future thesis. I will not use your real name in the disclosure of data findings. However, because I have no control over what you wish to say outside of this interview, I cannot promise you complete confidentiality should you decide to discuss your participation in the interview.

Please remember that, I will be recording this session in order to transcribe it later as not to miss any important points discussed. For this reason, it would be helpful for you to speak as clearly as possible - I want to be sure I get down everything that you want to say.

Do you have any questions before we begin the interview?

Introductory Comments

Could you please tell me a little bit about yourself and why you chose to participate in my study?

Transition Comments

Thank you. As you know, dementia affects a person's ability to perform everyday activities and many individuals who develop this disease will require the use of formal care. According to the Alzheimer Society (2010), approximately 500,000 Canadians have dementia today and it is the most significant cause of disability among Canadians over the age of 65. Dementia costs Canadian society many billions of dollars each year and forecasts predict that there will be, "65.7 million [people] in 2030 and 115.4 million [people] in 2050" (World Alzheimer Report, 2009) that have some form of dementia. Furthermore, forecasts predict that within 20 years, the worldwide prevalence of dementia will increase two-fold (ibid). With this being the case, it's important to address the current care provision for these individuals.

Key Questions/Probes:

1. *What dementia training have you received both in your school studies or otherwise?*

- Have you taken additional courses on dementia training that were not required of your workplace?

2. *Do managerial staff provide you with opportunities for further dementia education and training?*

- Do you feel that you receive an adequate amount of training shifts when are first hired to work on locked or behavioural/dementia care units?
- Do you believe that your facility provides adequate dementia education and training for nursing staff?
- Were you happy with the amount of education and training you received on dementia-specific content when you were first hired?
- What are the staffing ratios on your behavioural units?
    - Is one-to-one care to residents who demonstrate above average, aggressive behaviour provided when needed?
        - For how long?
            - Do you feel this is adequate?
- How are you kept up to date on current opportunities for dementia education and training?
- If you or other staff are having trouble providing care to particular residents, are there opportunities for you to receive further training?

3. *Are you satisfied with the dementia education and training opportunities of your workplace?*

- Why or why not?

4. *What are some strengths you see in the current provision of dementia training and education in your facility?*

5. *Where do you see room for improvement in the current provision of dementia training and education in your facility?*

- What types of further education would you find most helpful?

Conclusion

We have covered a lot of ground today. Before we finish, is there anything you would like to add or change in regards to your interview responses. I want to make sure I've gotten everything right.
Thank you for your participation.

Appendix G . Interview Guide for Family Members

Opening Comments

"Hello (participant's name). First off, I would just like to say thank you for agreeing to participate in this interview today. What we're going to be discussing, is the current education and training options that are provided and offered to nursing staff members in long term care facilities.The purpose of this project is to examine what education and training options are available and provided to long term care staff in Winnipeg, Manitoba who work directly with individuals who have dementia.

Since we have already gone over the formal consent process, we may begin the interview should you require no further clarification. That being said, is there anything you would like clarification on in regards to the consent form before we begin?

There are no right or wrong answers in this interview. In this research study, I have promised to keep the information you share with me confidential. This means that I (the researcher and interviewer) will not share any information from this interview with anyone other than my thesis advisor when using this data to inform my future thesis. I will not use your real name in the disclosure of data findings. However, because I have no control over what you wish to say outside of this interview, I cannot promise you complete confidentiality should you decide to discuss your participation in the interview.

Please remember that, I will be recording this session in order to transcribe it later as not to miss any important points discussed. For this reason, it would be helpful for you to speak as clearly as possible - I want to be sure I get down everything that you want to say.

Do you have any questions before we begin the interview?

Introductory Comments

Could you please tell me a little bit about yourself and why you chose to participate in my study?

Transition Comments

Thank you. As you may know, dementia affects a person's ability to perform everyday activities and many individuals who develop this disease will require the use of formal care. According to the Alzheimer Society (2010), approximately 500,000 Canadians have dementia today and it is the most significant cause of disability among Canadians over the age of 65. Dementia costs Canadian society many billions of dollars each year and forecasts predict that there will be, "65.7 million [people] in 2030 and 115.4 million [people] in 2050" (World Alzheimer Report, 2009) that have some form of dementia. Furthermore, forecasts predict that within 20 years, the worldwide prevalence of dementia will increase two-fold (ibid). With this being the case, it's important to address the current care provision for these individuals.

Key Questions

1. *Are you satisfied with the level of care your family member(s) are/is receiving at this facility?*

- Are you happy staffing ratio on this behavioural unit?
- From your experience, do you feel as though staff who work on this unit are adequately trained in working with your family member(s)?
- Do you feel that staff are approachable when you have concerns about the care your family member(s) is(are) receiving?

2. *Do staff seem calm and approachable on the unit?*

- Without providing any identifiable information on people, are there any interactions between staff and residents that you've seen that concern you?
- Without providing any identifiable information on people, are there any interactions between staff and residents that you've been happy with?
- What in particular troubled you or made you feel positive?

3. *Are you provided with any opportunities to receive information, education, or training on dementia from this facility?*

- Would you find this helpful?
- What types of education would you find most helpful?

4. *Are you satisfied with the care your family member(s) is/are receiving at this facility?*

- Why or why not?

5. *What are some strengths you see in the current provision of care to your family member(s) and dementia training and education in this facility?*

6. *Where do you see room for improvement in the current provision of dementia training and education for your family member?*

Conclusion

We have covered a lot of ground today. Before we finish, is there anything you would like to add or change in regards to your interview responses. I want to make sure I've gotten everything right.

Thank you for your participation.

Appendix H. Consent Form

Faculty of Health Sciences
College of Medicine
Department of Community Health Sciences
220 Human Ecology Bldg
Winnipeg, Manitoba
Canada R3T 2N2

UNIVERSITY OF MANITOBA

Phone (204) 471-69521
umsierab@myumanitoba.ca

Participant Consent Form

Participant's Name: ______________________________

Research Project Title: Addressing the Strengths and Gaps in Education and Training for Long Term Care Staff Who Provide Direct Care to Individuals Living With Dementia.

Date: June 1, 2015

Researcher:

Britt Sieradzki, Graduate Student, Department of Family Social Sciences
umsierab@myumanitoba.ca
[redacted]

Thesis Advisor:

Kerstin Roger, Professor, Faculty of Community Health Sciences
Kerstin.Roger@umanitoba.ca
204-474-6354

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Research:

The purpose of this project is to examine what education and training options are available and provided to long term care staff in Winnipeg, Manitoba who work directly with individuals who have dementia. I intend to look for areas where education and training for staff is strong and where it may be improved by interviewing staff members within long term care facilities and family members of residents who have dementia. By identifying and addressing both the strengths and gaps in current education and training, improvements may be made in order to achieve better care provision.

The current literature on aging has drawn attention to the anticipated increase in dementia prevalence and therefore, the increases in long term care facilities having to care for residents who have some form of dementia. My aim is to identify any gaps in education and training that appear amongst responses of participants in my study. As well, I am interested in seeing if any new themes emerge from your responses. The data collected from you for this study will be used to inform my future thesis work and for the publication and/or presentation of any findings from the study.

I am asking that you participate in a face-to-face, telephone, or Skype interview process that will last approximately one hour, held at a time convenient for you. These interviews will be tape recorded and transcribed verbatim by myself. I will also be taking personal notes during the interviews in the form of field notes for my personal use in analyzing the data that results from your participation in my study.

<u>Research Procedures and Recording:</u>

The purpose of this project is to gain an understanding of where the current provision of dementia education and training is strong in long term care facilities, as well as where it can be improved. My aim is to identify common themes in your responses, as well as the responses of other participants in my study. As well, I am interested in seeing if any new themes emerge from your responses. All of the data will be collected by myself, Britt Sieradzki both through the use of a voice recorder and transcription, and including my own field notes. All data collected from the study will be stored on a password protected USB stick and stored in a locked drawer at my home (128 Worthington Avenue). When utilizing any data on my computer, it will also be protected by having a password lock on my laptop. Interviews may also be taped using a digital voice recorder, and later transcribed verbatim. Notes may also be taken during the interviews. These notes will help me recall the discussion and also serve as a backup in case the digital recording malfunctions or is inaudible in any way. These data will be incorporated in my analysis if and as necessary. The only people who will have access to the raw data will be the Principal Investigator, myself (Britt Sieradzki) and my thesis advisor, Kerstin Roger.

<u>Risks and Benefits:</u>

I do not anticipate more than minimal risks to you as a result of participating in the study. I will explain before the interview begins that should you feel uncomfortable during a session, you are free to end participation at any time. I will also explain that there is no penalty if you decide not to participate. Should you choose to end your participation at any point, I will ask that you please let me know via the contact information I have provided at the bottom of this consent form. If you do choose to withdraw from the study at any point, any data collected from your participation will be destroyed and will not be used in the analysis of data or dissemination of the study's results. However, you may find it helpful to consider how efficient education and training can benefit nursing staff, family members, and residents with dementia. For this reason, the interview may be beneficial for you as it will give you a chance to explore your own perceptions on the phenomena and gain better insight to where there is room for improvement in dementia education and training, and care provision.

Anonymity and Confidentiality

Qualitative data will be collected from participants using face-to-face, telephone, or Skype interviews. Due to the nature of the recruitment of participants (requesting participation through the long term care facility and subsequently, through staff and family members), the identity of participants may become known should they choose to express their involvement in the study. Furthermore, other staff and family members may be aware of other participants should they choose to conduct face-to-face interviews with me on site. Participants will have the option of choosing where they want to have their interviews upon contacting me during recruitment and the consent process, so that confidentiality can be assured. Upon recruitment, it will be made clear to participants that they will be assigned pseudonyms in order to protect their identities and confidentiality in the findings of the study. All data collected from the study will be stored on a password protected USB stick and stored in a locked drawer at my home (128 Worthington Avenue). When utilizing any data on my computer, it will also be protected by having a password lock on my laptop. Interviews will be taped using a digital voice recorder, and later transcribed verbatim. Notes may also be taken during the interviews. These notes will help me recall the discussion and also serve as a backup in case the digital recording malfunctions or is inaudible in any way. These data will be incorporated in my analysis as necessary. The only people who will have access to the raw data will be the Principal Investigator, myself (Britt Sieradzki) and my thesis advisor, Kerstin Roger. Raw data will be stored for a period of at least five years, as it is anticipated that the data may be used to inform my thesis topic and be used in presentations and publications. The researcher (myself, Britt Sieradzki) and advisor may wish to access the anonymized data collected from this study (anonymized transcriptions and findings, not raw data) again in conducting future studies. Upon the completion of my thesis, if the data is not anticipated to be used again, all raw data will be destroyed. The electronic data will be erased/wiped clean from the digital storage device. Hard copy data will be shredded. I cannot provide an exact date for destruction as the researcher anticipates that the data may aid in future study of the proposed topic but it will not be kept past May, 2020.

Interview Feedback and Debriefing

There will be an opportunity at the end of your interview to add anything you feel may have been missed or provide clarity to anything you feel may not be accurately represented through your initial responses. This process of member checking will aid in making the research study more reliable and consistent. Should you want to review the transcripts from your interview, you may contact me using the contact information listed at the end of this consent form. I anticipate that it will take me approximately three days to have your interview fully transcribed. Should you request a copy to review yourself, you will have two weeks to inform me via contact information listed at the end of this form of any revisions you would like to have made. If I do not hear from you within two weeks of your interview, there will be no opportunity to make revisions as I will have begun the data analysis portion of the interview. I will send you a brief summary of my findings once all interviews have been held and the data have been analyzed and ask for feedback on this, which will be used towards my analysis. I anticipate sending the summary within three months of the data collection period but prior to beginning to write. You will be offered the opportunity to receive the summary either by regular mail or electronic mail.

Dissemination of Results to Participants

It is anticipated that the results of this study may be used to inform my future thesis topic and be used in future presentations and publications. When study results are shared, all findings will be presented in a way that does not identify you or any of the other participants.

Destruction of the Data

Raw data will be stored for a period of at least five years, as it is anticipated that the data may be used to inform my thesis topic and be used in presentations and publications. The researcher (myself, Britt Sieradzki) and advisor may wish to access the anonymized data collected from this study (anonymized transcriptions and findings, not raw data) again in conducting future studies. Upon the completion of my thesis, if the data is not anticipated to be used again, all raw data will be destroyed. The electronic data will be erased/wiped clean from the digital storage device. Hard copy data will be shredded. I cannot provide an exact date for destruction as the researcher anticipates that the data may aid in future study of the proposed topic but it will not be kept past May, 2020.

Contact for Future Clarification and Summary Results

If at any point, I require clarification from your interview or wish to conduct future interviews to inform my thesis project further, may I have permission to contact you again?

Please circle: YES NO

Thank you. Please provide the email address or mailing address below that you wish to be sent a summary of the results of the study:

Email: ____

Mailing address: ____________________________________

____

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw form the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Britt Sieradzki, Graduate Student, Department of Family Social Sciences
umsierab@myumanitoba.ca
[redacted]

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above named persons or Pinar Eskicioglu at the Human Ethics Secretariat at 204-474-7122 (Pinar.Eskicioglu@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature: ____________________________ Date: ____________________________

Researcher's Signature: ____________________________ Date: ____________________________