

**Communication Interactions of Health Care Aides
With Individuals with Dementia**

by

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Abstract

It is estimated that by 2038 over a million Canadians will be diagnosed with some form of dementia with nearly 443,000 living in long-term care facilities. Non-professional health care workers such as health care aides provide most of the direct care to these residents. The interaction skills of health care aides have a significant impact on the function, communication skills and wellbeing of residents with dementia. The purpose of this study using Strauss and Corbin's mode of grounded theory was to develop a mid-range theory to describe and explain how health care aides perceive and understand residents with dementia and how this perception impacts the way they interact with these residents. The sample for this study was made up of 24 health care aides who worked with residents with dementia in personal care homes in Winnipeg. Data from audiotaped individual and group interviews were analyzed using grounded theory methodology: open, axial and selective coding. The central category was "The Resident being perceived as a Respected Person". The resulting theory shows that when health care aides perceive the resident as a respected person with whom they have a relationship and as a care recipient with challenging behaviors, the health care aides use communication enhancement strategies and modify their caregiving to meet the resident's unique physical and emotional needs and challenging behaviors. The interactions of these health care aides in this study were consistent with the principles of person-centered care and the literature about communication and dementia. The facilitators of this perception of the resident were primarily the personal characteristics of the health care aide and the inhibitors were the time constraints, workload, and lack of support of peers and supervisors. This theory has implications for the training and supervision of health care aides and the organizational structures in which they work.

Key words: Health care aides; dementia; communication; long term care; personhood.

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Dedication

To Mary Judd

who taught us to see the “person” in the “patient” with dementia

To Dr. Elizabeth Townsend

who reached out and convinced me I could be a scholar

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Chapter One: Introduction

Statement of the Problem

Within the next twenty years, the number of Canadians diagnosed with dementia will increase dramatically. In a report commissioned by the Alzheimer Society of Canada (2010) it was estimated that 500,000 Canadians or 1.5% of the total population were diagnosed with dementia in 2008. This number was expected to increase to 1,125,200 people or 2.8% of the population by 2038. The same report estimated that 183,268 long-term care beds were occupied by residents with dementia in 2008 and that this number would grow to 249,268 by 2018 and further increase to 442,682 by 2038. Meeting the complex physical, emotional, and social needs of this population was emphasized as a growing concern for governments and health care providers, and the population at large.

Communication deficits are among the most common impairments experienced by individuals with dementia (Alzheimer Society of Canada, 2015; Bayles & Tomoeda, 2007; Byrne & Orange, 2005). Communication is defined as the use of symbols to receive and produce messages (Bayles & Tomoeda, 2007; World Health Organization, 2001). Within the *Canadian Model of Occupational Performance*, communication can be identified as an occupation that permits choice and control, serves as a determinant of health, and enables other occupations (Canadian Association of Occupational Therapists 1997; Wolf & Orange, 2009). The results of communication deficits include loss of choice and control in care decisions, loss of a sense of self and personhood, decreased functional performance and increased dependency (Baltes, Neumann, & Zank, 1994; Bayles & Tomoeda, 2007; CAOT, 1998; Kitwood, 1997; Ryan, Giles, Bartolucci, & Henwood, 1986).

Health care aides are the unregulated health care workers who provide from 70-90% of direct care to residents of nursing homes in Canada and the United States (Coogle, Parham, & Young, 2007; Cruttenden, 2006; Estabrooks, Squires, Carleton, Cummings, & Norton, 2014; Morgan, Stewart, D'Arcy, Forbes, & Lawson, 2005). They have the most communicative interactions throughout the day with residents with dementia. The interactions of these staff can result in improved quality of life and functional performance for residents of long-term care facilities (Caporalet, Lukaszewski, & Culbertson, 1983; Carpiac-Claver & Levy-Storms, 2007; Kemper & Harden, 1999) or disempowerment, depression and withdrawal (Baltes et al., 1994; Goldsmith, 1998; Kitwood, 1997; Orange, Ryan, Meredith, & MacLean, 1995; Ryan, Byrne, Spykerman, & Orange, 2005).

There are many factors that might influence the way in which health care aides come to understand and give meaning to the residents in their care. Factors that influence the communication styles adopted by health care aides in their interactions with residents with dementia are their attitudes and resulting behaviors towards residents (Bergener, 1996; Chrzescijanski, Moyle, & Creedy, 2007), as well as the training these workers receive concerning the social and emotional needs of care recipients with dementia (Cruttenden, 2006). In Canada and the United States, many of these workers are immigrants who do not have the language or cultural experience to prepare them to interact effectively with care recipients (Aitken, 1995; Browne & Braun, 2008; Coogle et al., 2007). As well, health care aides experience a range of work-life stressors including heavy workloads, inflexible work schedules, low pay, and stressful interactions with residents, family members, and co-workers (Browne & Braun, 2008; Goodridge, Johnston, & Thomson; 1996, Morgan et al., 2005). These circumstances may influence their ability to interact with residents in the provision of physical

care (Aiken, 1995; Levy-Storms, 2008). Another major stressor for health care aides is the physical and psychological abuse these workers experience from residents (Browne & Braun, 2008; Goodridge et al., 1996; Morgan et al., 2005). One outcome of this abuse is that health care aides may see the resident as a potential threat rather than someone in need of supportive interactions.

Kitwood (1990, 1997) stated that caregivers have to undergo a change in the way they perceive or give meaning to individuals with dementia. He continued that caregivers need to understand these individuals as persons with a whole range of human needs. Kitwood proposed that with this understanding caregivers can implement “positive care” interaction strategies that enhance the function and well-being of the individual with dementia (Ryan et al., 2005).

In their report, *Rising Tide: The Impact of Dementia on Canadian Society*, the Alzheimer Society of Canada (2010) emphasized the need for research focused on improving the quality of life for persons with dementia. They also recommended developing the expertise of care providers, including direct-care staff. To date, there have been few studies examining the interactions of unregulated staff and residents in long-term care facilities. This study addresses the recommendations of the report developed by the Alzheimer Society of Canada by exploring the interactions that currently occur between health care aides and residents with dementia in long-term care facilities in Winnipeg, Manitoba. The findings of this study draw attention to the need for modifications of training curricula for health care aides. It also shows the need for changes in the funding models and management policies of long-term care facilities so that this critically important group of health care workers receives the support and recognition they need to continue providing up to 90% of the care for frail elderly residents with dementia.

Purpose of the Study and Research Questions

The purpose of this study was the development of a mid-range theory to describe and explain how health care aides perceive and understand care recipients with dementia and how these perceptions and understandings are reflected in the interaction strategies of health care aides with these care recipients. Qualitative methods were adopted for this study since this research paradigm permits exploration of the socially constructed realities of individuals (Denzin & Lincoln, 2005). Grounded theory methodology according to the mode developed by Strauss and Corbin was chosen for a number of reasons. First, this method leads to the development of theory in the absence of previous theory (Strauss & Corbin, 1998). Secondly, it provides a systematic method to study the social actions of the health care aides such as their interactions with residents with dementia (Creswell, 2013; Speziale & Carpenter, 2007). This mode of grounded theory situates the researcher in the work and incorporates the professional and personal experience of the researcher (Annells, 1997; Denzin & Lincoln, 2005). Finally, grounded theory moves the research beyond description to the development of theory that can guide future actions, possibly resulting in positive change to factors related to the social processes being studied (Speziale & Carpenter, 2007).

Grounded theory is based on the principles of symbolic interactionism. Symbolic interactionism provides an interpretive perspective to research (Jeon, 2004). This approach was developed by Herbert Blumer and George Herbert Mead to explain how humans develop socially derived meanings for “objects” in their environment such as other individuals or groups of people (Blumer, 1969; Mead, 1934). The combination of the two theoretical perspectives of grounded theory and symbolic interactionism was suited to the development of a midrange theory that describes and explains how health care aides perceive and confer meaning to the

residents in their care and modify their interactions with these residents based their perceptions of the residents (Annells, 1997; Glaser, 1978; Jeon, 2004; Strauss & Corbin, 1998).

Research questions. Four initial research questions were identified.

1. How do health care aides perceive and present individuals with dementia?
2. What factors facilitate this process?
3. What factors inhibit this process?
4. What are the consequences of this process?

Definitions

Dementia. In this study, the term dementia refers to a syndrome resulting from progressive neurological conditions that lead to the destruction of brain cells and result in impairments of cognition, function, and communication. Persons with this condition may experience behavioral changes that impact their interactions with others (Bayles & Tomoeda, 2007; Canadian Association of Occupational Therapists, 1998).

Communication. Verbal communication employs the use of words and language while nonverbal communication refers to the use of facial expression, touch and vocal characteristics such as voice pitch and loudness (Bayles & Tomoeda, 2007; Kemper, 1994; World Health Organization, 2001). Through communication, health care workers such as health care aides can teach and encourage care recipients to perform occupations, such as self-care and mobility activities (CAOT, 1997; Townsend & Polatajko, 2013; Christiansen, 1999; Wolf & Orange, 2009).

Health care aides. Health care aides are unregulated health care workers who provide direct care to long-term care residents. Direct care activities include assisting residents with self-care and feeding activities, transporting residents and answering requests for assistance (Aitken,

1995; Coogle et al., 2007). Health care aides provide up to 90% of the direct care for residents in long-term care facilities throughout Canada (Cummings et al., 2013; Estabrooks et al., 2014) and therefore have the most direct contact with these residents than other staff. The quality of the interactions of these health care aides with the residents can have a significant influence on the function, communication and quality of life of these residents (Kitwood, 1997; Wolf & Orange, 2009).

Study Context

Personal care homes in Winnipeg

Definition of personal care homes. In Manitoba, long-term care facilities are known as personal care homes (PCH). Banerjee (2007), writing about long-term care facilities in Canada, defined long-term care as a range of services that attempt to meet the physical, emotional, recreational, and social needs of persons who can no longer take care of themselves. Only one percent of Canadians live in long-term care facilities, with most of them being over 85 years of age (Banerjee, 2007).

Regulation of personal care homes in Manitoba. Provincial funding for personal care homes in Manitoba is administered through the regional health authorities (The Regional Health Authorities Act, 2014). In addition, residents pay a per diem accommodation rate. In 2001, the minimum daily accommodation rate was \$25.80 (Banerjee, 2007). In 2005 the Personal Care Homes Standards Regulations were enacted (The Personal Care Home Standards Regulation, 2005). These regulations came under the Manitoba Health Services Insurance Act (2015) and linked licensing and funding of personal care homes to the compliance of standards for safety and quality of care. This act applies to both publically and privately funded facilities (Canada Health Act, 1984). The regional health authorities are responsible for administering the

provincial funding for personal care homes for insured services that are defined by the provincial government. They are also responsible for inspecting personal care homes to monitor compliance with the standards (The Regional Health Authorities Act, 2014). The Personal Care Home Standards Regulations include definitions of the application assessment form, of all types of caregivers, of the resident and the resident's designate, and eligibility criteria for admission (The Personal Care Homes Standards Regulation, 2005).

In 2006, there were 10,000 personal home care beds in Manitoba in 122 facilities, with most of these being in Winnipeg. In Manitoba, 84% of PCHs are not-for-profit, with 15% privately owned and for-profit facilities (Banerjee, 2007). Banerjee also reported that 53% of the PCH facilities in Manitoba provided Level 3 or the highest level of care and provided 4.22 hours of care per day per resident, of which 1.68 hours were provided by registered nurses or registered nursing assistants. At the time of writing his report, Banerjee found that Manitoba had the highest rate of PCH placements in Canada, with 126 beds per 1000 people over the age of 75 years (Banerjee, 2007)

Characteristics of residents of personal care homes in Winnipeg. In 2013 the Canadian Institute of Health Information (CIHI) published the analysis of the data entered into the Resident Assessment Instrument-Minimum Data Set, Version 2.0 (RAI-MDS2.0) from all Canadian provinces and territories for the year 2011-12. Since the only Manitoban facilities collecting data for the RAI-MDS were in Winnipeg, the data from this report is directly applicable to the four facilities represented in this study. The demographic profile of PCH residents in Winnipeg is presented in Table 1 while Table 2 sets out selected clinical characteristics of these residents. The average age of these residents is 84 years.

Table 1.
Profile of PCH Residents in Winnipeg

<u>Demographic Information</u>	<u>%</u>
Female	55
Younger than 65	5
85 and older	55

Note: From CIHI, 2013

Table 2.
Selected Clinical Characteristics of PCH Residents in Winnipeg

<u>Clinical Condition</u>	<u>%</u>
Bladder incontinence	67
Diagnosis of dementia	61
Musculoskeletal Disease	51
Bowel incontinence	45
Limited or no social engagement	46
Daily pain	25
Diabetes	21
Signs of depression	18

Note: From CIHI, 2013

The CIHI report revealed that nearly 15% of residents had experienced a fall within a time frame of 30 days. The report identified depression, behavioral symptoms and pain as the greatest barriers to quality of life for residents. However, facilities in Winnipeg had one of the lowest indicators across Canada for the use of antipsychotic medication for residents with a diagnosis of psychosis.

Characteristics of residents with severe and moderate dementia. The CIHI (2013) report showed that in Winnipeg, over 60% of assessed residents in reporting PCHs had symptoms of moderate to severe dementia (Table 2).

Dementia is an umbrella term for a variety of brain disorders with symptoms that include the following: a) loss of memory; b) loss of judgment and reasoning; and c) changes in mood and behavior.

A common symptom for individuals with middle-stage or moderate dementia is an impairment of cognitive abilities. Memory problems can include the person not remembering his/her name, forgetting recent events and not being able to recognize family members and friends. Disorientation and inability to concentrate are other common symptoms (Alzheimer Society of Canada, 2015).

One of the predominant characteristics of individuals with moderate dementia is a change in mood and emotions with the individual demonstrating emotions such as suspicion, sadness, depression and frustration. These emotions can change to anger, hostility and agitation. Conversely, the person can become withdrawn and apathetic. Common behaviors of persons in this stage are restlessness, pacing, wandering and repetitive questioning. These persons may also experience delusions, hallucinations, and uninhibited behaviors (Alzheimer Society of Canada, 2015).

Individuals in late-stage dementia demonstrate severe cognitive impairment with an inability to process information or to be oriented to time and place. Their communication issues include the inability to comprehend what is said or to make a verbal response. These persons need assistance with all self-care activities and usually require assistance with mobility and transfers. Many are confined to wheelchairs. Impairments of swallowing and weight loss are common symptoms of the disease process at the middle stage of the illness. Interventions include caring for the skin and body, ensuring safe swallowing during assisted feeding, and maintaining bowel and bladder function (Alzheimer Society of Canada, 2015).

The latest stage of dementia progresses to end-of-life, with a gradual decline of circulatory function and an increased incidence of skin breakdown, a build-up of secretions, increased sleepiness and a further reduction of appetite. However, it is understood that the person at this stage still experiences emotions as well as increased sensitivity to environmental elements such as light and sound (Alzheimer Society of Canada, 2015).

To review, the majority of residents of PCHs in Winnipeg have a diagnosis of some stage of dementia. These residents demonstrate a combination of deficits that include cognitive, communication, and functional performance deficits as well as behavioral changes. They present complex care needs and eventually, palliative or end-of-life care.

Summary

This chapter has been used to present the statement of the problem addressed by this study and the purpose of the study, including the research questions and definitions of terms used in the study. Information about the study context has also been provided that includes a discussion of personal care homes in Winnipeg and a description of the residents of these facilities. In Chapter Two, the literature used for this study will be reviewed.

Chapter Two: Literature Review

This chapter will present the literature reviewed throughout the development of this study. Literature serves specific purposes in grounded theory methodology. Therefore a discussion of the use of literature in grounded theory will precede the literature review.

The Use of Literature in Grounded Theory Research

Unlike quantitative research, an exhaustive review of the literature is not necessary prior to undertaking a qualitative study (Strauss & Corbin, 1998). Instead, Glaser (1978) wrote that the researcher is to come into the study with few predetermined ideas, especially those related to existing hypotheses. However, Chenitz (1986) stated that the literature review can be used in the development of the research project to provide information about the scope, purpose, and background of the study and to demonstrate how it will add to the existing knowledge or theory about the topic. The risk literature presents to the study is that the researcher may filter his/her observations through existing theory or “force” data to meet existing ideas or theories (Strauss & Corbin; 1998). However, during data analysis, literature can be used to sensitize the researcher’s interpretation of the data, to stimulate questions, to permit comparisons with concepts in the literature and to verify and add dimension to emerging concepts and categories (Glaser, 1978; Strauss & Corbin, 1998). Returning to the literature at the completion of the study can serve to confirm the findings and determine how the findings fit with the existing knowledge as well as how they contribute to the field of study. Therefore, the principles inherent in grounded theory dictate the use of literature throughout the progress of the study.

Reviews of the literature about health care aides as well as the literature about the communicative interactions between caregivers and individuals with dementia were used in the preparation of the proposal for the study. The literature about personhood and the person with

dementia was used to achieve theoretical sensitivity during data analysis (Strauss & Corbin, 1998)

This literature review includes literature about health care aides, communication and dementia and personhood and the person with dementia. The review of the literature about health care aides includes the following topics: a) description of health care aides in Canada and the United States; b) essential competences and training of health care aides; c) health care aides in the organizational structure ; d) health care aides and person-centered care; e) the attitudes and behaviors of health care aides; f) health care aides and continuing education; and g) ethical issues related to conducting research with health care aides. The topics addressed in the review of the literature regarding communication and dementia includes: a) definitions of communication; b) communication and dementia; c) speech accommodation theory; d) communication theories of aging; e) environmental influences and caregiver communication; and f) communication and caregiving. The literature about personhood and the person with dementia presents ten concepts of personhood as they apply to persons with dementia.

Health Care Aides

Description of health care aides. Up to 90% of the direct care provided for residents in long-term care facilities in Canada and the United States is provided by health care workers who are not professionally regulated (Coogle et al., 2007; Cranley et al., 2012). In the literature, these workers are called nursing assistants (Aitken, 1995; Coogle et al., 2007), resident attendants (Cruttenden, 2006), direct long-term care workers (Browne & Braun, 2008), and nursing aides (Levy-Storms, 2008; Morgan et al., 2005). In Manitoba, they are called health care aides (HCAs) (Winnipeg Regional Health Authority, 2004). This is also the designation used by trade schools and colleges that provide training for these workers in Manitoba (Canadian Health Care Aide

Schools, 2009; Herzing College, 2016; Red River College, 2016; Robertson College, 2017; Workplace Education Manitoba, 2009). In a report issued by the Association of Canadian Community Colleges (ACCC), other titles were used for these health care providers across Canada including health care assistant (British Columbia and Yukon), personal support worker (New Brunswick), and continuing care assistant (Nova Scotia and Saskatchewan) (ACCC 2012). However, within the ACCC report, these titles were combined in the term “personal care provider” (ACCC, 2012).

In Manitoba, health care aides are employed in personal care homes that fall within the definition of hospitals and chronic care institutions set out in the Canada Health Act (1984). These facilities are administered through the provincial Health Services Insurance Act (2015). In Manitoba, the Personal Care Homes Standards Regulations (2005) come under the Health Services Insurance Act. The staffing guidelines for personal care homes in Manitoba were established in 2004 and stipulated 3.6 paid nursing hours per resident per day (Manitoba Centre for Health Policy, 2004).

All employees of personal care homes in Manitoba are required to abide by the provisions of The Personal Health Information Act (2013) and the Protection of Persons in Care Act (2009). The latter act requires that all known or suspected incidences of abuse to residents of personal care homes must be reported to the Office of the Protection of Persons in Care.

Health care aides represent a major segment of the employees of long-term care facilities in Canada (Aubry, Etheridge, & Couturier, 2013; Banerjee, 2007, Estabrooks et al., 2014). Studies about health care aides employed in long-term care facilities have been conducted in both Canada and the United States. Estabrooks and her colleagues conducted a study of 1,381 health care aides from a representative sample in 30 urban personal care homes in the three

Canadian Prairie Provinces (Estabrooks et al., 2014). They found that of the health care aides who participated, over 90% were female, with the majority being over 40 years of age. Of the respondents from Manitoba (n = 336), nearly 70% were born outside of Canada with 60% having English as a second language. Although most health care aides were married, many were single parents or the single wage earner for family members either in Canada or abroad (Morgan et al., 2005).

In the United States (US), a comprehensive study of aides working in home care, hospitals, and nursing homes was conducted using data from the 2000 census (Montgomery, Holley, Deichert, & Kosloski, 2005). This study revealed that most care aides were female (90%), over 40 years of age, with over half being non-White or Hispanic and with 77% being born in the US. About 15% of these American nursing home aides spoke a language other than English at home. Nursing home aides were found to have lower education levels than hospital aides, with 30% having less than a high school education, earning less than national median annual earnings and having a high school education or less (55%). Browne and Braun (2008) added that some care aides had professional certifications from another country that were not recognized in the US and these workers were forced to find employment as care aides in positions that were low-paying, stressful, and frequently part-time or contract positions and without benefits. The authors observed that health care services depended largely on these workers while failing to recognize their contribution.

In personal care homes, health care aides provide care for frail elderly residents with multiple chronic medical conditions and some degree of cognitive impairment (Banerjee, 2007; Canadian Institute for Health Information, 2013). Health care aides assist these residents with personal care activities such as mobilizing, dressing, bathing, grooming and eating. In addition to

providing direct care, health care aides are expected to observe and report changes in residents' health, functioning, and behavior (Aitken, 1995; Browne & Braun, 2008). In the course of providing care, health care aides acquire extensive knowledge about each resident, including his or her personal experiences, abilities and limitations. The care provided by health care aides impacts many aspects of the resident's well-being including pain management, skin care, urinary health and food intake, as well as mental status and general quality of life (Cranley et al., 2012; Kitwood, 1997).

In a needs assessment study to describe Alberta's health care aide workforce, Cummings and her colleagues researched related published and unpublished organizational reports and grey literature from a number of countries, including Canada, with most of the literature coming from the United States (Cummings et al., 2013). The authors also interviewed health care executives, post-secondary private and public institution administrators, association executives, and health services researchers. They found that the tasks of health care aides in long-term care, community and acute care facilities fitted into five categories: 1) patient contact tasks; 2) physical tasks; 3) clerical tasks/administrative; 4) non-patient contact; and 5) tasks similar to registered nurses. Patient contacts tasks, such as bathing and feeding, were most often referred to in reports about the utilization of health care aides but their responsibilities ranged from oral care to venipuncture and catheterization. In addition, the staffing levels of registered nurses, licensed practical nurses and health care aides had shifted between 1997 and 2007 with health care aide staffing increasing and the use of registered and licensed nurses declining. In the same study, it was reported that health care aides were not respected, valued or supported by some employers and other nursing professions. There was also the observation that registered nurses and licensed

practical nurses may not be trained to provide adequate supervision for health care aides (Cummings et al., 2013).

Essential competencies, training and regulation. In their study of unregulated health care workers in Canadian long-term care facilities, Estabrooks and her colleagues found there were no national educational requirements for these workers (Estabrooks et al., 2014). In a previous effort to address this issue, the ACCC (2012) conducted an environmental scan of training programs for personal care providers in Canada. The purpose of this scan was to build consensus in the development of national educational standards for personal care providers. At the time of the scan, as well as currently, the development of these programs was a provincial responsibility. The sample used for this environmental scan was made up of 74 educational institutions from all the Canadian provinces and territories. The results of the scan included information about the essential competencies of personal care providers and provincial and territorial educational programs as well as registration policies in each of the provinces.

The ACCC (2012) environmental scan led to the development of a list of essential competencies of personal care providers that was developed from the curricula of training programs across Canada. According to this list, personal care providers should be competent using knowledge from the following course topics: common health challenges, body systems and functions, person-centered care for clients, personal care skills, cognitive and mental health care, chronic conditions, communication skills, and dementia care. This list of care-related competencies differed from that developed by Human Resources Skill Development Canada (HRSDC) and the Industry Workforce Development, Competitiveness Training and Trade, Province of Manitoba for Workplace Education Manitoba (2009). This list identified ten essential skills for health care aides including: 1) reading and understanding written text; 2) using

documents to find or record information; 3) using numbers and thinking mathematically; 4) using the written word to create a clear message; 5) using oral communication when talking to others to give or receive information such as asking questions; 6) explaining or giving presentations; 7) working with others; 8) using a thinking process to solve problems, organize and plan; 9) using computers; 10) and participating in life-long learning (Workplace Education Manitoba, 2009). These competencies appeared to prepare the health care aide to cope within the institutional environment rather than to develop skills specific for the provision of patient care.

The ACCC's environmental scan also revealed discrepancies in the content and length of educational programs across Canada. Mandatory provincial/ territorial personal care programs were provided in six regions: Alberta, British Columbia and Yukon Territory, Newfoundland and Labrador, Nova Scotia, Ontario, and Quebec. The length of time used to deliver these programs varied from a minimum of 485 hours to over a thousand hours of combined classroom and supervised clinical placement training. However, no quality assurance programs were in place to ensure that provincial programs followed prescribed ministerial curricula. Some provinces and territories utilized institutionally approved curriculum standards.

Manitoba presently does not have a provincially mandated training program for health care aides but the public and private technical colleges have collaborated to adopt similar learning outcomes. The current programs for preparing care aides for the workforce are provided through the publicly funded Red River College and private colleges including Herzig and Robertson Colleges. These programs involve both classroom instruction and supervised clinical placements. The programs last from 20-26 weeks. For example, Robertson College currently provides 20 weeks of classroom instruction and six weeks of supervised clinical placement over 26 weeks. It previously offered an enhanced 32 week program that included training in

interpersonal skills and allowed students more time to complete their studies. However, this program has been discontinued (Robertson College, 2016). The curriculum for health care aide training at Red River College includes classroom instruction in activities of daily living, gerontology, community and long-term care, interpersonal relationships, safety, and *Non-Violent Crises Intervention*. Supervised clinical experience is also included, with the program being delivered over 20 weeks (Red River College, 2016). Manitoba Health is currently reviewing the health care aide programs offered by private institutions, using the public colleges as a measure of learning outcomes (ACCC, 2012).

One of the concerns identified in the study of health care aides in the three Prairie Provinces (Estabrooks et al., 2014) was that in none of the provinces were these workers regulated. Only five provinces maintained registries of health care aides: British Columbia, Alberta, Ontario, Quebec, and Nova Scotia. However, only British Columbia and Ontario have implemented mandatory registration. British Columbia, Ontario, Quebec and Nova Scotia have minimum education requirements. There is no provincial registry for health care aides working in Manitoba.

Recommendations to address concerns about the essential competencies, training, and regulation of health care aides are found in the report by Cummings et al., 2013. This report was developed to describe the complexity of Alberta's health care aide workforce. The authors reviewed published and unpublished formal organizational reports and grey literature about from many countries, including Canada. The literature was categorized according to the following topics: health care aide vocational education, supply, demand, use, injury and illness. Although the literature represented a number of countries, including Canada, most of the literature was from the United States. The researchers also interviewed key stakeholders, including healthcare

executives, post-secondary private and public institution administrators, association executives and health care researchers. A primary finding of this research was the increasing expectation that health care aides, as unregulated health care workers, would work autonomously without clear roles or a defined scope of practice, performing functions formerly assigned to nurses or licensed practical nurses. Concerns about the competency of these workers as reported by participants included: a) factors related to their initial certificate training; b) ongoing education needs once employed; c) unclear roles and scope of practice; and d) the increasing expectation of health care aides to work autonomously providing direct patient care. The recommendations made by the study group included: a) determining a clear definition of the roles of health care aides that reflect their increased scope of practice; b) updating the list of core competencies and the *Competency Assessment Profile Tool* for health care aides; c) updating and standardizing the curriculum across Alberta; d) employers providing English-as-a-second- language training; e) additional funding for employers to provide ongoing education tailored to the needs of their patient population; f) the development of a provincial mandatory registry of all practicing and student health care aides; and g) the establishment of an organization that would formally represent health care aides and possibly maintain the registry.

Health care aides in the organizational structure. Health care aides, as employees of long-term care facilities, form a part of the facility's organizational structure. The role of non-professional caregivers as opposed to licensed nurses was explored in a study about the caregiving attitudes of nurses and nursing assistants in nursing homes in Ohio (Schirm, Albanese, Garland, Gipson, & Blackmon, 2000). Focus groups were conducted with 36 licensed nurses (25 licensed nurses, 11 licensed practical nurses) and 40 nursing assistants. The focus groups with the licensed nurses were conducted in four different nursing homes. Separate focus

groups were conducted with nursing assistants who were attending continuing education programs. In this study, the authors described nursing homes as formal organizations developed to provide care to the frail elderly. Within these organizations, there are an interrelated set of statuses of employees arranged in a hierarchical division of labor that is designed to accomplish the purpose of the organization as efficiently and effectively as possible. The status set includes nurses, licensed practical nurses and nursing assistants. In order for the system to work smoothly, it is important that each status understand the role of others as well as their own role. This understanding is necessary for accomplishing the complex task of caring for frail elderly. Throughout the focus groups, the nurses agreed that nursing assistants were crucial to the provision of good quality care and acted as the eyes and ears of nurses. They provided necessary information to the nurses who were ultimately responsible for the quality of care. The nursing assistants agreed that their relationships with nurses influenced the quality of the nursing assistant's work. The issues the nursing assistants identified in these relationships were: 1) differing role expectations for nurses; 2) status differences between nursing assistants and licensed nurses; and 3) the supervisory styles of nurses. For example, the authors found that the rigid division of labor caused nursing assistants to be more aware of the status difference between themselves and the nurses. The nursing assistants observed that while the nurses received more pay, the nursing assistants provided the care and often identified problems to the nurses who did not respond consistently to the nursing assistants. As a result, the nursing assistants felt undervalued. The nurses were also aware that, because of their other duties, they did not always respond immediately to the concerns presented by the nursing assistants and expected the nursing assistants to be more assertive and tenacious when requesting the nurse's attention. The authors referred to this form of communication as a "game" with the object of the

lower status person being able to tell the higher status person what to do without appearing to do so. Both groups agreed on the need for improved communication and cooperation between licensed nurses and nursing assistants. The authors recommended an extended orientation for nursing assistants under the guidance of a licensed nurse. This orientation would serve to build the nursing assistant's technical and interpersonal skills for working with frail elderly while also teaching them about the role of the licensed nurse. The authors also suggested an orientation period for licensed nurses that focused on the skills needed to supervise less skilled staff. The authors ended by emphasizing the need for a supportive and nourishing work environment built on mutual respect, communication and dependability (Schirm et al., 2000).

In a study conducted by Cranley and her colleagues about health care aides as employees of institutional organizations, it was observed this group of workers was a valuable resource which was not always recognized by the organization (Cranley et al., 2012). In their study about engaging front-line staff in developing a program for safer care for residents, a group made up of twenty senior decision makers, registered nurses/ care coordinators, managers and educators, and another group of fifty health care aides were each asked to prioritize a list of care domains related to resident safety. The two groups agreed on the top five priorities: pain management, behavior, depression, skin care, and nutrition (Cranley et al., 2012). This study confirmed Cruttenden's (2006) observation that health care aides have critical thinking abilities grounded in their experience with residents and the culture of the facility.

Aubry and his colleagues conducted a study on facilitating organizational change with nursing assistants in long-term care (Aubry et al., 2013). The authors began the study with the assumption that nursing assistants (health care aides) played an important role in long-term care facilities because they had the most direct contact with residents and that the introduction of

innovative care practices required involvement of all members of the interdisciplinary team. They were interested in finding out if teamwork served as a deterrent to change or a lever for change. Specifically, the authors wanted to learn how newly recruited nursing assistants were integrated into the team and the process of transmitting informal work strategies to these new workers. The authors conducted twenty-three in-depth recorded interviews with nursing assistants from two long-term care facilities in Quebec. There were twelve health care aides from one facility and eleven from the second facility. The authors used a semi-inductive analysis approach to analyze the data from the interviews. They found that the nursing assistants who were already employed had developed tightly knit teams that worked closely with each other, sharing and distributing workload in order to complete the day's tasks. These veteran nursing assistants oriented the new workers, requiring the new workers to develop the same pace of work as the other assistants. The veteran assistants showed the new workers various care techniques that reduced the time required for care tasks, thus helping the new workers achieve the required pace of work. The authors concluded from observing the level of cohesion of the teams of nursing assistants that these teams were potentially either a deterrent or a facilitator of change. They recommended that to implement changes in care practice managers should not mandate change, thereby creating resistance from the nursing assistants, but develop collaborative relationships to promote the nursing assistants supporting change (Aubry et al., 2013).

As previously observed, along with their changing and expanding roles, health care aides tend to work autonomously (Cummings et al., 2013). The lack of contact between health care aides and other levels of health care providers is supported in the literature. McCloskey, Donovan, Stewart and Donovan (2014) conducted a multi-center, cross-sectional study in which they observed the work flow of all levels of care providers in seven different nursing homes in a

Canadian province. They observed that nurses had the least variation in their role, while licensed practical nurses had the greatest variation, with both categories performing tasks that could safely be passed on to others. These authors found it surprising that the registered nursing assistants, who had the most contact with the resident, were sometimes not present at meetings, did not document their findings, or engage in dialogue with other health care providers. Aubry and his colleagues (2013), in their study of implementing change in long-term care institutions, also observed that health care aides in these settings worked apart from other health care providers. These authors found that health care aides, when faced with heavy workloads and time constraints, formed homogenous work groups and developed group strategies to reduce the amount of time taken to perform required tasks. These strategies were sometimes contrary to facility policy. The workers passed these strategies on to new recruits, establishing expectations the newcomers were expected to meet. For example, these work groups adopted the practice of reducing their discussion with residents during toileting to reduce the amount of time taken for this task. This was despite facility policy to respect residents and attend to their needs, including relational needs. The findings from these studies also support those of Banerjee and his colleagues (Banerjee et al., 2012). They wrote that the work of Canadian front-line staff in long term care facilities is highly stratified, with rigid time schedules and heavy workloads.

Work life stressors of health care aides. As has been already indicated, work-life stress is a significant reality for health care aides in both Canada and the United States. In a study conducted in Winnipeg about work-life stress experienced by nursing assistants, Chappell and Novak (1992) defined a stressor as any internal demand or external environmental demand that exceeds the adaptive capacity of the person experiencing the stress. They defined stress as a lack of fit between the needs of the individual and the demands of the environment. One stressor that

has been identified in the literature is the lack of support from co-workers and supervisors. For example, Cruttenden (2006) observed that non-professional workers looked to the registered nurses and licensed practical nurses for leadership that was not always available. Other stressors included heavy workloads, inflexible work schedules, low pay, and conflict with residents, family members, and co-workers (Browne & Braun, 2008; Morgan et al., 2005). In another study of Canadian health care aides, it was found that these non-professional workers, who provide 70-90% of the direct care to nursing home residents, worked within staffing levels and skill sets that had not kept up with resident care needs, including the needs of residents with dementia. The result was heavy workloads of staff and decreased quality of life for residents (Estabrooks et al., 2014).

In focus groups conducted with licensed nurses and then with nursing assistants (Schirm et al., 2000), the nurses described the work environment of the nursing assistants as extremely demanding, noting the problems the assistants faced in “trying to please the nurses, the management, and the families. It’s overwhelming” (Schirm et al., 2000, p. 287). Both groups agreed that staff shortages contributed to work stressors. However, the nurses laid some responsibility for this on the nursing assistants, saying that the assistants were not always dependable in reporting for their scheduled shifts. Both groups agreed on the importance of showing up for work, being on time, and taking responsibility for one’s actions (Schirm et al., 2000).

Banerjee and his colleagues (2012) explored the concept of “structural violence” in their study of residential care workers in Canada and Scandinavia. They surveyed front-line care workers in three Canadian provinces (Manitoba, Ontario, and Nova Scotia) and four Scandinavian countries (Denmark, Finland, Norway, and Sweden). After sending survey

questions to 948 unionized Canadian front-line workers and 360 Scandinavian workers, they conducted focus groups with workers in each of the three Canadian provinces. They found the working conditions of Canadian front-line workers to be more stressful than their Scandinavian counterparts. For example, they found that Canadian workers had less training than their Scandinavian counterparts. The Canadian workers also experienced heavier workloads, more rigid work schedules, lower autonomy and status, and greater exposure to verbal and physical violence from residents and their family members than did the Scandinavian workers. The authors attributed this difference to long-term care being funded nationally in the Scandinavian countries, with greater resources available to these facilities. This difference reflected the Scandinavian social policy of identifying long-term care as a public responsibility rather than a family responsibility as it is in Canada. They also identified that the tasks of Scandinavian front-line workers were less stratified than those of comparable workers in Canada. For example, Scandinavian workers shared a range of tasks between different levels of workers and had greater autonomy as they carried out their work (Banerjee et al., 2012).

Frequent interruptions while performing their tasks and lack of organization in the use of staff time was found to be another work stressor for health care aides. In a study about organizational resources in long-term care facilities, an underlying assumption was that time is a valuable resource for any institution and the use of time by health care aides has direct implications for the quality of care provided to residents (Mallidou, Cummings, Schalm, & Estabrooks, 2013). Using observations of seven health care aides on a long-term care unit during the day shift over nine weeks in a six month interval, researchers determined that 52% of the health care aides' time was spent in direct care activities with 29% used in "other" activities. Only 1% of the aides' time was spent socializing with residents. Much of the time spent in direct

care and other activities was broken into one, two, and three-minute tasks that represented interruptions and lack of continuity in task completion. Much time was spent in finding, moving, and storing supplies. On an eight-hour shift, each health care aide spent 69% of the day working without contact with other staff. The most common theme from the interviews with the health care aides was heavy workloads and lack of time to complete tasks. The authors recommended a reorganization of staff time to enable health care aides to have time to be “present” with the resident. The health care aides would then be able to get to know the resident and provide emotional support and more mobility activities. These interventions have been found to reduce depression and to add quality of life for residents in long-term care. Mallidou and her colleagues also suggested that a reorganization of the aide’s time might change the unit culture to improve collaboration, and staff satisfaction and perhaps reduce staff turnover (Mallidou et al., 2013).

Aitken (2005) provided a compelling analysis of the work-life stress of nursing assistants in British Columbia. In this study, Aitken obtained data from participant observations of nine nursing assistants working in a long-term facility in British Columbia over the summer and fall months of 1992. She also conducted interviews with three care-coordinators who supervised these nursing assistants. Aitken estimated that a nursing assistant in a long-term care facility in British Columbia completed up to forty lifts and transfers each shift, with this translating into the movement of up to two thousand pounds per day. She also observed that the values of nursing home management reflected the medical model of healthcare with medical technology being more valued than caregiving activities. She concluded that quality of care was defined from the perspective of medical and professional experts with a “top down” approach to care management. In Aitken’s view, this approach did not always result in quality of service for the resident and devalued the work of nursing assistants. For example, she observed that nursing

assistants experienced reduced job satisfaction as a result of mandatory time schedules that did not permit them to meet the residents' needs. There was also the perception by supervisory staff that nursing assistants were wasting time when talking to each other. However, Aitken believed the demands of teamwork required a strengthening of workplace relationships through staff members being able to talk to one another. The development of these relationships was already challenged since many of the workers were immigrants with English as a second language and representing a diversity of cultures.

Physical and psychological abuse. One of the disturbing revelations about the work-life stress of health care aides was the amount of physical and psychological abuse they routinely encountered. Goodridge et al. (1996) conducted a study of 126 nursing assistants in a long-term-care facility in Winnipeg. The participants completed a questionnaire related to nursing assistant-resident conflict and aggression towards nursing assistants by residents. Subjects reported that conflict with residents was most often related to the resident wanting to go outside the facility or to caregiving activities related to personal hygiene. On an average, nursing assistants in that facility could expect to be physically assaulted by residents 9.3 times per month and verbally assaulted 11.3 times per month. The types of physical abuse included being pushed, grabbed, shoved or pinched, being hit or almost hit with an object, having an object thrown at the nursing assistant, or being kicked or bitten. Types of verbal abuse included being insulted or sworn at or being threatened. A statistically significant relationship was found between conflict with residents and resident aggression from residents. Not all incidents of abuse were reported (Goodridge et al., 1996).

In a study of 355 nursing aides in rural nursing homes with and without Special Care Units (SCU) in Saskatchewan, it was found that nursing aides employed in a facility with a SCU

had less frequent exposure to aggressive behaviors and less distress when these behaviors were directed at them (Morgan et al., 2005). Higher risk of being assaulted was associated with working with residents with dementia who were not in an SCU. Other factors associated with increased risk were having a permanent position, experiencing increased job strain, and feeling inadequately prepared for dementia-care (Morgan et al., 2005).

Identifying that physical aggression is a burden to both the residents and staff members of nursing homes, Leonard, Tinetti, Allore, and Drickamer (2006) wanted to determine potentially modifiable resident characteristics associated with physical aggression and then to correlate these characteristics with verbal aggression. They conducted a cross-sectional study of nursing home residents in five states who had at least one annual Minimum Data Set assessment implemented during 2002. A total of 103,344 residents met study criterion. The average age of the residents in the study was 84 years, with 75.9% being women. Of this number, 7,120 (6.9%) had been physically aggressive in the week before their annual Minimum Data Set assessment. The researchers found the strongest causal association of aggressive behaviors was with depression, followed by delusions, hallucinations, and constipation. The researchers also found some co-existence of physically aggressive behaviors with verbal abuse, with 38.4% of residents who were verbally abusive at least once in the week before their assessment also being physically abusive in the same time period. The results suggested that the treatment of these conditions might reduce physical aggression among nursing home residents.

Non-pharmacological interventions to reduce aggressive behaviors of residents. The relationship of resident aggression and the unmet needs of the resident were addressed in a study of the non-pharmacological treatment of agitation occurring with nursing home residents with dementia (Cohen-Mansfield, Libin, & Marx, 2007). This was a placebo-controlled study of 167

elderly residents of twelve nursing homes in Maryland. Six of the nursing homes were treatment facilities and six were control facilities. Agitation was defined as inappropriate verbal, vocal, or motor activity that was not associated with the person's needs or confusion. These behaviors were frequently addressed with the use of physical restraints and/or pharmacological management. Unmet needs included: a) pain; b) feelings of loneliness or isolation; c) boredom; and d) sensory deprivation. The non-pharmacological interventions included : a) modifications to the physical or social environment to decrease agitation or trigger positive responses; b) removal of physical restraints; c) provision of individualized music or other sensory stimulation; d) real or simulated social contact such as family videotapes or one-to-one social interactions; e) family audiotapes in simulated presence therapy; f) art activities; g) hand massage; and h) real, toy, or robotic assisted animal-assisted therapy. The background medical and social history of each resident receiving treatment was studied and each resident was assessed for his/her cognitive status and possible depression. Interventions were chosen to address identified unmet needs of the resident. The implementation of this individualized, non-pharmacological approach resulted in a statistically significant decrease in overall agitation in the intervention group compared to the control group. These interventions were also associated with the resident's increased levels of pleasure and interest. The implications for the nursing home system included the need to provide training and mentoring of nursing home personnel and their being given sufficient time and resources to match the person with the appropriate interventions and provide the interventions (Cohen-Mansfield et al., 2007).

In another study of non-pharmacological interventions to address the agitation of seniors with dementia, a study was conducted to investigate the perceptions of long-term care staff regarding the current use of non-pharmacological interventions (NPIs) for the reduction of

agitation in seniors with dementia and to find the facilitators and inhibitors that guide NPI use (Janzen, Zecevic, Klooseck, & Orange, 2013). A combination of qualitative methods (surveys, focus groups, and interviews) was used to gather data from forty-four staff from five long-term care facilities. Eight of the participants were personal support workers with the remaining sample comprised of nurses, registered nurses, recreation specialists, Directors of Care and Unit Coordinators. The survey questions referred to non-pharmacological interventions including calming music, physical activity, pet therapy, reading groups and reminiscence therapy. Nurses and a portion of front-line staff were inclined to support the use of medication because of its quicker results in reducing problem behaviors and increasing the safety of all residents. The most commonly used NPI by front-line staff was re-approaching and distraction. The common barriers to the use of NPIs were the perceived lack of time, low staff-to-resident ratios, and the unpredictable and short-lasting effectiveness of NPIs (Janzen et al., 2013).

Belgian researchers explored the use of spatial and sensory interventions to reduce agitation (Van Vracem, Spruytte, Declercq & Van Audenhove, 2015). Seven types of environmental interventions for agitation in dementia were reviewed in the literature. These were the use of light, smell, temperature, nature, color and glare, and spatial configuration. Three panel discussions were conducted with five family caregivers, twelve professional home-care workers and ten professional caregivers working in nursing homes. The panel members supported the use of daylight, natural elements, and domestic smells.

A review of the literature about non-pharmacological interventions for managing the agitation of nursing home residents was conducted by Jutkowitz et al. (2016). They studied the literature about non-pharmacological interventions used in nursing homes and assisted living facilities to reduce agitation and the aggressive behaviors of residents with dementia. Their

premise was that behavioral and psychological symptoms tend to occur in clusters and include depression, psychosis, aggression, agitation, anxiety, and wandering. The authors referred to agitation as excessive motor activity associated with irritability and wandering. They identified aggression as a sub-type of agitation that consisted of verbal and physical abuse. These behaviors resulted in negative outcomes for both residents and caregivers and were frequently managed with antipsychotic medications. The researchers reviewed articles about various types of non-pharmacological interventions. After assessing 4,855 citations, the reviewers settled on nineteen eligible studies for analysis in the review. Several categories of non-pharmacological interventions were represented in the studies. They were: a) dementia care mapping [3 studies]; b) person-centered care [3 studies]; c) protocols to reduce the use of antipsychotic and other psychotropic medications for agitation and aggression [3 studies]; d) emotion centered care [2 studies]; and e) “unique comparisons” [11]. The unique comparisons group represented a variety of caregiver training interventions and could not be conceptually grouped. There was insufficient evidence to show whether non-pharmacological care-delivery interventions were any more effective than usual care in improving the symptoms of agitation and aggression in nursing home and assisted living residents. The reviewers recommended that the research community should continue to fund studies of non-pharmacological interventions (Jutkowitz et al., 2016). None of the studies previously described in this literature review were included in the study.

In a current systematic review of randomized clinical trials of the use of non-pharmacological interventions (Livingston et al., 2014), 33 studies were reviewed for validity and calculated standardized effect sizes. These writers found some evidence-based strategies that could be used in care homes and which had effects up to six months afterwards. These included person-centered care, communication skills, training and adapted dementia care mapping. The

authors concluded that these non-pharmacological interventions had to be properly supervised when implemented. They particularly mentioned interventions that helped staff members communicate with residents and understand and meet the resident's needs (Livingston et al., 2014).

Finally, the use of non-pharmacological methods in responding to the behavioral and psychological symptoms of dementia (BPSD) was discussed by Azermai (2014). In this article, non-pharmacological interventions, particularly person-centered care and exercise therapy were recommended as the most effective methods to be used to prevent or reduce the occurrence of challenging behaviors by persons with dementia living in long-term care facilities. Only when these are proven ineffective, should pharmaceuticals such as antipsychotics be use used in responding to BPSD (Azermai, 2014)

Interactions strategies to prevent aggressive behaviors. Snellgrove and colleagues (Snellgrove, Beck, Green, & Mc Sweeney, 2015) from the School of Nursing at Arkansas State University conducted a study using semi-structured interviews to explore the strategies developed by certified nurses' assistants (CNAs) to prevent and manage resident-to-resident violence in nursing homes. The inclusion criteria for the CNAs were having witnessed an episode of resident-to-resident violence and being employed at the nursing home that was the study site (Snellgrove et al., 2015). The authors could not find a conceptual framework that specifically addressed resident-to-resident violence. However, they identified that many residents were no longer able to communicate their needs. They therefore used the *Need-Driven Behavior-Compromised Model* (NDBM) to guide the study. The overriding theme of the interviews was, "Putting the Residents First". The CNAs made a conscious effort to consider what it would be like for he/she or a beloved family member to be in the place of the resident while the CAN

administered care. Within this theme were three related subthemes: a) Knowing the Residents; b) Keeping Residents Safe; and c) Spending Quality Time. The results of the data analysis showed that the CNAs, despite the absence of formal education or training in dealing with residents who may become violent, developed their own strategies to prevent and manage challenging behaviors. Their primary tool for predicting violence was getting to know the resident. This strategy included identifying individualized activities that kept residents happy and not bored. The findings supported Kitwood's theories of personhood (1997) that emphasized social interaction and its impact on behavior. The findings revealed that when the CNAs knew the resident, they could predict periods of agitation. Closely related to this theme was that of Spending Quality Time. This was a strategy that helped to prevent boredom that been shown to trigger violence. These findings supported the importance of empathizing with residents to decrease episodes of violence. It also supported the CNAs having more input in resident care planning.

The use of restraints with residents with challenging behaviors. One of the concerns addressed by provincial governments and regional health authorities as well as researchers is the use of restraints with residents who wander or become violent. A physical restraint is any device, materials, or equipment that is attached to a person and prevents free body movement. The most common restraints are vests, pelvic or waist restraints that can be attached to chairs or raised bedrails (Pracy & Cheung, 2004). These authors explored the relationship between patient autonomy and the use of physical restraints by studying the literature about the effectiveness of restraints. The finding resulting from of this exploration was that the use of restraints was not effective in protecting the welfare of patients. Instead, it was found that the use of restraints without the consent of the patient was morally unjustified and an unequivocal violation of the

patient's autonomy. Hughes and Common (2015), in their article about ethical issues related to caring for patients with dementia, stated that all care provided to persons with dementia, including advanced dementia, must be guided by compassion, honesty, and prudence.

The province of Ontario passed the Patient Restraints Minimization Act (2001) which applies to every hospital approved under the *Public Hospitals Act*. The act forbids the restraint or confining of a patient or the use of a monitoring device on a patient unless it is necessary to prevent serious harm to the patient or others. However, the use of alternative measures that impose less control on the patient can be used when found necessary (Ontario, 2001)

The Winnipeg Regional Health Authority (WRHA) has developed the *Restraints in Personal Care Homes (Safe use of)* policy (Winnipeg Regional Health Authority, 2015) which is applicable to all sites and facilities where WRHA services are delivered. This policy refers to four kinds of restraint: a) chemical restraints or pharmaceuticals such as sedatives, hypnotics, antipsychotics, antidepressants or anxiolytic medications; b) emergency restraints used when the resident poses a risk to him/herself or others; c) environmental restraints or barriers to personal movement that confines the resident to specific areas, such as their room and that include the removal of a cane or walker, or applying brakes to a wheelchair to prevent the resident from wheeling away; and d) physical or mechanical restraints which include hand/arm restraints, chairs or splints that prevent rising, chair trays that cannot be removed, back-fastening seat belts, or two full or three-quarter bed rails in the up position. The policy states that restraints may be used when required in the clinical management of the resident but that these restraints pose an inherent risk to the resident's physical safety and psychological well-being. Controlling a resident's freedom in any way is a restraint and carries with it a responsibility for caregivers to use a high degree of forethought, caution, and attention when using such restraints. The chosen

restraint would be the least restraint possible. Staff members will be trained in the use of the restraint. Restraints cannot be used without the prior consent of the resident or their Substitute Decision Maker (Winnipeg Regional Health Authority, 2009).

The College of Nurses of Ontario, in their *Practice Standard for Restraints*, refers to the efforts of increasing numbers of facilities to achieve restraint-free care. Changes in institutional policies have led to education programs and assessment tools that assist caregivers in finding alternatives to restraints. The use of restraints is an intervention of last resort and is based on meeting the needs of the client (College of Nurses of Ontario, 2009)

Staff training and the management of agitated behaviors. One intervention to help staff members manage the agitated behaviors of residents with dementia is staff training programs. Studies have been conducted to explore the effectiveness of these programs. McCallion, Toseland, Lacey and Banks (1999) conducted a study to evaluate whether a *Nursing Assistant Communication Skills Programs* (NACSP) would result in an improvement in the resident's psychological wellbeing along with a reduction of problem behaviors. The secondary objective of the study was to identify if the education programs resulted in increasing in the nursing assistants' knowledge about dementia and their ability to respond to problem behaviors. The study was conducted in two skilled-care nursing homes. A total of 88 nursing assistants were divided into a treatment group (n=39) and a control group (n=49). Data was collected from 105 residents with dementia divided between the two institutions. Each resident had a diagnosis of dementia and at least one problem behavior. After a six-month assessment period, one group of nursing assistants was given the NACSP. Participants in both treatment and control groups were assessed after nine months. Results showed a significant drop in resident depression after three and six months. Nursing assistants had an improved ability to manage verbally aggressive

behaviors. However, improvements in managing physically aggressive behaviors lasted only three months. These results suggested the nursing home should continue to implement the NACSP and that these sessions would also provide an opportunity for the nursing assistants to discuss issues that arose with new residents. Following the study, the investigators met with the nursing assistants. The researchers concluded that overall participation in the NACSP produced only a short-term effect on the nursing assistants' ability to manage problem behaviors (McCallion et al., 1999).

Another study about the reduction of the agitation of residents with dementia that involved a training program was conducted by Magai, Cohen and Gomberg (2002). They based their study on the premise that persons with late-stage dementia may be especially sensitive to the emotional signals of others. Participants were 91 dementia patients who had been assessed by the Minimum Data Set and 31 staff caregivers. The study was designed to assess whether training caregivers in sensitivity to nonverbal communication could enhance the mood and reduce the agitation of residents while improving the psychological wellbeing of caregivers. Residents and staff of three nursing homes were randomly assigned to either a group given nonverbal sensitivity training, a behavioral placebo group that received instruction about dementia and a wait-list group. The training sessions were taught by a clinical psychologist and consisted of ten one-hour sessions that focused on understanding the emotions and nonverbal communication of the dementia patients. Residents were assessed at the beginning of the study to establish a baseline and at four week intervals thereafter. These assessments recorded emotional symptomatology as reported by caregivers as well as positive and negative facial expressions that occurred during face-to face interviews with staff members. These expressions which were coded by trained research staff. The staff participants were assessed with the *Brief Symptom*

Inventory (BSI) which measured depressions, anxiety, and somatic symptoms. Results showed that the residents' symptoms of depression, agitation and behavioral and psychological symptoms did not differ in the three groups. However, residents who were cared for by staff who had received the training sessions exhibited more positive affect as observed by the trained coders. However, negative affect declined in all three groups of residents. The caregivers in the training and placebo groups showed a decline in symptomology (Magai et al., 2002). Whether this intervention decreased agitated behaviors of residents is unclear.

A third study aimed at determining the value of education programs to reduce the agitated behaviors of residents with dementia was conducted by Chrzescijanski, Moyle and Creedy in Australia (2007). This study examined the impact of a staff education program on aggression as displayed by persons with dementia in residential care. The staff training program was designed to change staff attitudes and perceptions towards the care management of the person with dementia. The resident acted as his/her own comparison in an interrupted time series. The education intervention was called the *Emotional Responses as Quality Indicators* (ERIC). Forty-three residents and 85 staff were involved in the study. The findings indicated the persons with dementia displayed cues about impending physical aggression. However, these cues were frequently ignored by staff, suggesting the staff might not have recognized anger as a legitimate human response in the context of the disease process (Chrzescijanski et al., 2007).

Health care aides and person-centered care. The model of person-centered care as a means by which caregivers provide emotional and psychological support for persons with dementia was first introduced by Tom Kitwood in the 1980's and 1990's (Kitwood, 1990, 1997,1998). He developed a philosophy and approach to caregiving built on Carl Roger's model of person-centered psychotherapy (Passalacqua & Harwood, 2012). Through his work, Kitwood

created a new culture in dementia care, moving away from the standard medical paradigm of practitioners seeing dementia as the consequence of a neurological disorder and therefore only addressing the person's physical needs. Kitwood believed that enhanced personhood and well-being were the central goals of caregiving (Pulsford, Duxbury, & Carter, 2016). This approach to providing care for elderly persons with dementia incorporated the concepts of personhood and what Kitwood called "positive person work" (Kitwood, 1997, p. 89). Positive person work involved the caregiver's recognition of the person with dementia as being a person, the use of negotiation, collaboration, play, stimulation or interactions that involved the senses, celebration, relaxation, encouraging the person to be creative, and facilitation (Kitwood, 1997, pp. 89-91). Although Kitwood wrote in the 1990s, person-centered care continues to be recognized as a way of providing psychosocial support to persons with dementia residing in personal care homes (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Mitchell & Agnelli, 2015; Passalacqua & Harwood, 2012; Pulsford et al., 2016). Since health care aides provide up to 90% of the interactions with residents with dementia, they are the caregivers with the most opportunity to implement person-centered care practices. The following is a discussion of person-centered care as it applies to the care of persons with dementia who are resident in long-term care facilities.

A model of the three fundamental qualities that caregivers should possess to practice person-centered care and promote the wellbeing of persons with dementia was developed by Pulsford, Duxbury and Carter (2016). They based their model on Kitwood's ideas of personhood and the need for the person with dementia to be supported emotionally, socially and psychologically. Central to this model is the concept of "cognitive security". Cognitive security is defined as "the subjective feeling of a person with dementia that they perceive meaning in their experience and can respond to that experience to meet their immediate needs" (Pulsford et

al., 2016, p. 39). Since cognitive security is a subjective feeling, it may not always be recognized or understood by others. However, cognitive security is closely associated with feelings of wellbeing. The opposite of cognitive security is cognitive insecurity, which occurs when persons cannot find meaning in their experience. Caregivers must be able to judge the person's level of cognitive security in each situation. The qualities required by a caregiver to do this are empathy with the person, person-centered attitudes, and a compassionate approach. Having the quality of empathy requires the caregiver to have interpersonal sensitivity, self-awareness, and knowledge about the resident. Interpersonal sensitivity permits the caregiver to interpret the actions of the person with dementia as attempts to find security. When a caregiver possesses self-awareness, he/she is able to look beyond his/her own perspective of the person's experience and instead use the person's frame of reference. Having knowledge involves knowing the person and their life history, understanding the effects of dementia upon the person, and being able to attribute the person's behavior to meeting some need.

Person-centered attitudes include the caregiver interpreting dementia as a disability rather than a disease. With this perspective, the caregiver is more likely to promote the person's remaining strengths instead of attending only to the person's physical needs. Person-centered attitudes also require the caregiver to see the person with dementia as another person and not an "ex-person" (Puslford et al, p. 40). As well, the caregiver is able to put the needs of the person with dementia at the forefront and thereby attend to their social and psychological care.

The third component of this model of fundamental caregiver qualities is a compassionate approach. Again, the caregiver is required to possess interpersonal sensitivity while adopting a personal manner and interaction style that promotes the person's cognitive security. This involves responding to the person's wishes and preferences, being able to overcome personal

constraints and become less inhibited in responding to the person while having knowledge that leads to creative solutions based on the caregiver's empathetic understanding of the person. This knowledge informs the caregiver when to be directive or facilitative while being able to judge the appropriateness of care interventions.

Touhy (2004), in writing about nurses' interactions with persons with dementia, offered support for Kitwood's concepts of person-centered care and knowing the person with dementia. She wrote about the need for nurses to appreciate the persistence of self into advanced dementia and to look beyond the disease to the person within. Touhy stated it was important for nurses to appreciate persons with dementia as living in the moment rather than concentrating solely on managing the person's care. However, contrary to Pulsford et al. (2016), Touhy suggested that rather than attempting to understand the person as they once were, it is more important to concentrate on the person with dementia as they are at the present time. She called for a re-focusing of care away from the physical and cognitive losses resulting from dementia and suggests instead that nurses develop the ability to be in a relationship with the person with dementia. Touhy referred to the "nursing as caring theory", with the nurse coming to know the person and to understand that the person with dementia "is and remains caring, human, whole, and complete" (Touhy, 2004, p. 45). She gave as an example the nurse seeing anger and aggression not as disruptive behavior but as the person's honest effort to seek help and an expression of trust that the nurse would be able to address their need.

Person-centered care and life-history review. The ability of caregivers and family members to interpret the resident with dementia as a person has been associated with their knowledge of the resident's past life. (Egan, Munroe, Hubert, Rossiter, Gauthier, Eisner...Rodrique, 2007; McKeown et al., 2010; Pulsford et al., 2016; Wolf, 2006). In a previous

study of the perceptions of personhood and the person with dementia, I developed ten concepts about personhood from a review of the literature about personhood and the person with dementia. I then interviewed nine adult children of persons with dementia. The participants were recruited through the Manitoba Alzheimer Society. I asked the participants open-ended questions about how they remembered their parent before and after the onset of the parent's dementia. Through a combination of thematic, inductive, and matrix analysis, I found that all ten concepts of personhood were represented when the adult children discussed their perception of their parents both before and after the onset of dementia. All informants continued to understand their parents as persons, with some believing the parent continued to be the same person while others believed the parent to be a changed person. All the informants relied heavily on the stories of their parent's past occupational achievements, such as farming, owning a business, being a parent, or being a volunteer, when describing their parent. Although each of the adult children had spent time and energy caring for their parent, none of them identified embodiment alone as a means of establishing their parent's personhood. The most important support to the perception of the parent as a person was the parent's life history. This supported the concepts of the parent as a "being" entity or a spiritual entity with uniquely human qualities who experienced meaning in their life as well as an "occupational identity" (Wolf, 2006, p. 132).

A number of benefits have been attributed to caregivers having knowledge about a resident's life history. This knowledge can be used to help caregivers discover the identity of the resident, to promote conversation during care, to help the caregiver understand the resident as a person who has tried to make the best of the circumstances of his/her life and to assist caregivers in developing warm and empathetic relationships with the resident (Egan et al, 2007. p. 26). Egan and her colleagues conducted a study about the impact of exploring the life histories of

residents with a history of verbal and physical aggression. Four residents were recruited from two long-term care facilities in Ontario. The residents had a diagnosis of dementia and had been identified by staff members as having aggressive behaviors that distressed the resident or the staff members. The research assistants, experienced nurses undertaking graduate training, met with family members to collect the life history of each of the four residents. From the information from family members, the assistants developed a one-page summary, which they shared with the family members. The life history was then placed in the chart for staff to read. Staff members recorded the resident's behaviors using an observation grid and definitions of aggressive behaviors formulated by the research assistants and staff members. These observations began 14 days prior to the introduction of the life history in the chart and at least 21 days following. The results from these observations were mixed with two residents showing a reduction of aggressive behaviors and two showing little change. Ten staff members were interviewed, seven of whom were unregulated health workers who provided direct care to the residents and three who were licensed nurses. The authors found that the impact of life history knowledge on care could include: a) long-term care staff members having greater knowledge of the history of residents with dementia; b) the development and sharing of life stories that included both happy and sad memories assisting staff in forming more empathetic, genuine relationships with residents; c) the development of life stories requiring staff to work sensitively with family members, ensuring that the family were comfortable with the final version of the life story; and d) a greater understanding of the resident's life story resulting in long-term care staff providing more individualized care to residents. These behaviors, which included caregivers having a greater knowledge of the resident with dementia, forming empathetic relationships with

the resident and providing individualized care, were all identified as indicators of person-centered care (Egan et al., 2007).

In their study of life histories or life-story work which was conducted in three British long-term care settings, McKeown and her colleagues (McKeown et al., 2010) also found that life-story work has the potential to enhance person-centered care for older people with dementia and their families. Using a multiple case design, they conducted interviews with four people with dementia living in four separate long-term care facilities, their family caregivers and care staff. Three main themes emerged from data analysis along with a common theme of maintaining personhood. The first theme, "from patient to person", indicated that when staff knew the personal information about a resident, they saw the resident in a different way. They began referring to the resident as a "person" rather than as a "patient" and developed a greater understanding of the person. The second theme, "Can you hear me?" was evident when family members were able to share information about their loved one. This seemed to provide a voice for the person with dementia, sometimes literally, as occurred when a gentleman with dementia made voluntary comments about photographs of himself from an earlier time. The third theme, "pride and enjoyment", referred to the enjoyment experienced by care staff who participated in the life-story work. Although the residents did not overtly express that they enjoyed being part of the study, they were able to indicate pride in seeing pictures of themselves in former times or knowing that others were paying attention to their history. The authors concluded that this study reflected Kitwood's emphasis on knowing about the person's life history to allow the identity of the person to be maintained (McKeown et al., 2010).

Person-centered care and the relationships between caregivers and residents. An inherent component of the model of person-centered care is the development of relationships

between caregivers and residents with dementia (McGilton, 2004; McGilton & Boscart, 2006; Ericsson, Kjellstrom, & Hellstrom, 2011). A definition of relationships drawn from psychology referred to basic, long-lasting connections between people. These are founded on strong emotional ties and a sense of commitment to the other person and are not generally bound by strict rules (Reber, 1995). A more specific definition of relationships between disabled and non-disabled persons was provided by Bogdan and Taylor (Bogdan & Taylor, 1989; Taylor & Bogdan, 1989). In a qualitative study of the relationships of people with mental retardation and non-disabled people, the authors defined the relationship between these persons as follows: “An accepting relationship is defined here as a relationship between a person with a deviant attribute, in this case mental retardation, and a nondisabled person, which is long-standing and characterized by closeness and affection and in which the deviant attribute, or disability, does not have a stigmatizing, or morally discrediting, character in the eyes of the nondisabled” (Taylor & Bogdan, 1989, p. 27). The College of Registered Nurses of Manitoba (CRNM) refers to the relationship between registered nurses and clients as a therapeutic relationship. This relationship is “a planned, goal-directed and contractual connection between a registered nurse and a client for the purpose of providing care to the client in order to meet the client’s therapeutic needs” (College of Registered Nurses of Manitoba, 2011, p. 1). There are five characteristics of this relationship. The first characteristic, respect, forms the basis of the relationship and supports the dignity, worth, and rights of the client. It leads to the recognition of the client’s unique personal experience and intrinsic worth. Trust is the second characteristic, with the client being able to have confidence that the nurse has the requisite skills to meet the care needs of the client and will protect the confidentiality of the client. The third characteristic, empathy, requires the nurse to be empathic and understanding of the client while maintaining appropriate emotional distance. The

nurse must recognize the imbalance of power in any relationship between the nurse and the client and the potential for abuse arising from the nurse's specialized skills and access to confidential information about the client. The fifth characteristic of this relationship is professional intimacy. This refers to the psychological, emotional, and physical closeness that exists between the nurse and client and which requires the nurse to observe professional boundaries between the nurse and client. Professional boundaries identify the parameters of this relationship. A boundary violation occurs when the client's needs are no longer the focus of the therapeutic relationship, opening the possibility of negative outcomes for the client (CRNM, 2011).

Within the context of person-centered care, the nature of relationships between caregivers and care recipients with dementia was studied by McGilton (2004). She referred to Kitwood's work in her discussion of the behaviors of residents with care providers, and observed there is no definition for these relationships. However, these relationships differ from the usual relationships between individuals because of the cognitive vulnerability of the persons with dementia. McGilton stated that the needs of the resident should dictate the nature of the relationship with the caregiver and determine if the relationship should be therapeutic or more social and personal. The provider's interest in forming a relationship with the resident is also important since care providers are more likely to initiate these relationships and have more power in the relationship. McGilton had previously conducted a study with 25 residents about their perspectives of their relationships with caregivers. She found that their opinions varied, with some residents wanting a kin-like relationship with caregivers, while others were not interested in this type of relationship because they continued to have close relationships with family members. McGilton determined that the care provider must try to identify the importance of the relationship from the resident's perspective. When discussing the relationships between persons with dementia and their

caregivers, McGilton made the following observations: a) these relationships are likely to be different than relationships with persons who do not have dementia; b) the relationships people need when they are older may be different that when they were younger; c) residents with dementia are emotionally as well as physically vulnerable, with impaired cognition and insight; d) residents with dementia have reduced interactional or relational abilities such as communication deficits which impair their ability to express themselves easily and share in the usual give-and-take interactions characteristic of other types of relationships; and e) residents still retain the ability to reciprocate in relationships as evidenced by their abilities to express emotion, initiate social contact, and display affection and social sensitivity. Based on the principle that relationships and relational behaviors are strongly linked, McGilton developed a *Relational Behavior Scale* (RB Scale) that measured three domains of relational interactions: 1) staying with the resident during the care episode; 2) altering the pace of care by recognizing the person's rhythm and adapting to it; and 3) and focusing beyond the task (McGilton, 2004). Staying with the resident included behaviors such as being in close proximity to the resident, echoing the resident's sounds, using various forms of touch that were comfortable for the resident and even sitting beside the resident. Altering the pace of care was demonstrated by the caregiver being flexible and adjusting their care actions to the ability of the resident to respond. Focusing beyond the task required that the caregiver to be sensitive to the resident's feelings by watching their expression and by speaking to the resident regardless of the resident's ability to respond. The common factor of these domains was the caregiver demonstrating empathy and reliability in their interactions with the resident (McGilton, 2004).

In a second study, McGilton and Boscart (2006) studied the perception of relationship between care providers with both residents in long-term care facilities and their families. In the

literature review conducted about the relationships between care-providers and residents, the authors found that these relationships are unique because they can last over a long time and are institutionalized in nature. A close relationship can only develop if it is based on mutual trust and occurs in a friendly and supportive environment. Caregivers can facilitate the process by using communication strategies that enhance the self-esteem and autonomy of the resident and lead to the resident's sense of comfort and well-being. The literature about residents revealed that moving into a long-term care facility is a major life change for residents, resulting in them experiencing physical and psychological problems. The literature suggested that the relationships between caregivers and residents was often formal and existed out of necessity, with only a small number of caregivers considered friends or confidants. Literature representing the families' perspective revealed that family members felt the relationship between their relative and the caregiver was paramount and that caregiving involved more than a set of assigned tasks. Families expected staff members to focus their energy on maintaining the psychosocial health and dignity of the resident. Family members also wanted to establish a relationship with caregivers to enhance the care provided to their family member, expecting to work closely with staff and have their knowledge and experience valued.

McGilton and Boscart (2006) interviewed 25 residents, 25 family members and 32 care providers (six registered nurse, 15 health care aides, and 11 licensed practical nurses). Data was analyzed using a comparative method. The authors found that care providers, residents and family members were able to describe what they saw as constituting a close care provider-resident relationship. Care providers believed that feeling connected with the resident and experiencing reciprocity in the relationship was important. Being connected involved knowing the resident and was essential to understanding the resident's needs and emotions and meeting

these needs. They defined “reciprocity” as a mutual togetherness, making things work in the day-to-day world, with give-and-take between the partners. Residents perceived the caregiver as a confidant who had their best interests at heart and who took the initiative and did things without being asked. The residents put a heavy value on the caregiver being reliable, available when needed and knowing what to do. Family members defined the relationship between the caregiver and resident as one in which the caregiver had a caring attitude, conveyed genuine concern and provided personal attention.

McGilton and Boscart also presented the factors that had an influence on the relationship between caregiver and the resident and their families. The care providers focused briefly on organizational constraints such as limited time and inadequate staffing. However, the care providers found that the resident’s cognitive and communication deficits and lack of social interactional skills were more important inhibitors to their being able to develop a relationship with the resident. They found it was easier to have a relationship with a resident who interacted with them. They seemed to look for a connection between themselves and the resident. For example, caregivers felt enabled to have relationships with residents when they could exchange personal stories, including stories about each other’s families. These relationships were also facilitated by the resident appreciating that the caregiver was trying to do their best. However, the care providers agreed that their heavy workload reduced the time they had to give to residents. The residents and their families focused on the barriers to developing a close relationship with caregivers. They spoke of feeling ignored when caregivers acted as if they were not committed to the relationship. Residents talked about caregivers who did not listen to their questions or who never asked non-care related questions. This left the resident feeling neglected. Family members observed caregivers stayed away from residents who spoke another language.

Sometimes residents felt that care providers were not interested in a close relationship, with this perception supported by the caregiver's actions and words. "I can live without you, but you can't live without me" (McGilton & Boscart, 2006, p. 2133). Some family members observed that the resident only represented care tasks to the caregiver. However, some residents were not interested in developing relationships with caregivers, either because they were not interested at their age or because they never developed close relationships with others. Residents and family members also spoke of the need for the caregiver to be trustworthy. Characteristics that displayed non-trustworthiness were technical incompetence, not fulfilling the resident's needs and the care provider not being reliable. The latter was a major concern for family and residents and was exemplified by caregivers who did not respond to the resident's needs in a timely manner, who failed to keep promises, or who did not turn up at all.

McGilton and Boscart ended their article by identifying what the relationships between residents and caregivers should look like. They list the types of possible relationships as: a) therapeutic; b) surrogate; c) friendly; d) professional; and e) personal and familial. They suggested that the needs of the resident should determine the type of relationship. For example, therapeutic relationships for residents who were troubled or depressed would be best provided by registered nurses. Residents who had lost many family members might prefer a more personal relationship while others with intact families might prefer a friendly relationship. The authors introduced the term, "meaningful relationships", with the interpretation depending on the needs of the particular resident. These types of relationships require caregivers to become aware of the meaning of the relationship for each resident they care for. The authors suggested that creating dyads of residents and caregivers with time set aside for the development of relationships may facilitate these meaningful relationships. The potential hazards to this arrangement might be the

over-involvement of staff with residents and staff becoming upset when the resident died. Some care providers spoke of distancing themselves from residents in order to protect themselves from this eventuality. The authors observed that if meaningful relationships were the crux of quality care then training programs should be developed to help caregivers to function within these relationships and then to step out when necessary.

In the articles by McGilton and McGilton and Boscart, there were four interventions suggested to support front-line caregivers in the use of effective relational behaviors: 1) continuity of caregivers for each resident; 2) supportive supervision of caregivers, with unit managers demonstrating empathy and reliability in their interactions with direct caregivers; 3) workplace policies and practices that move away from an emphasis on task orientation to recognition of effective interactional care; and 4) adequate staffing to support the development of meaningful on-to-one relationships (McGilton, 2004; McGilton & Boscart, 2006).

In a study by Ericsson and her colleagues, relationships between caregivers and residents were explored when time was made available for the development of what McGilton and Boscart (2006) referred to as meaningful relationships. This study was conducted in Sweden and explored caregiver relationships with persons with moderate to severe dementia (Ericsson et al., 2011). The data for their study came from 24 videotapes of relational time (RT) sessions with caregivers and persons with dementia. They also carried out 24 interviews with persons with dementia and eight interviews with professional caregivers. Their study was developed on the following premises: a) an essential element of person-centered care is that the caregiver attempts to develop a relationship with the person with dementia; b) the ability to create and maintain relationships is critical to the person with dementia's sense of identity and feelings of personhood; c) persons with dementia want relationships with other people; and d) negative

attitudes towards persons with communication deficits are relational barriers. The context of their study was a method called “Relational Time” (RT) which they defined as “a way of activating/stimulating the person with dementia that begins with the unique person’s interest, wishes and capacity and where focus is on the person” (Ericsson et al., 2011, p. 65). Relational time was seen as an evolution of patient-centered care. The researchers understood the process of developing relationships as a social process and therefore used constructivist Grounded Theory for their study. The core category of their findings was “Opening up”. The strategies for achieving the core category were “Assigning time”, “Establishing security and trust”, and “Communicating equality”. In assigning time, the person was assigned time by the caregiver but also indirectly by the institution. This assigning of time was separate from the casual chatter that occurred during caregiving, with the caregiver having an opportunity to be relaxed and focused on the resident. The caregiver gave no signal of the caregiver being stressed or rushed. As a result, the resident experienced feelings of significance and felt important because someone had set time apart for them. In the strategy of establishing trust, the caregiver approached the resident in a non-threatening manner and took pains to adjust to the person’s ability to respond. This was not always easy with residents with severe dementia who were withdrawn and uncommunicative. However, the caregiver would persist, changing his/her approach to fit the resident’s ability to respond. Communicating equality represented the caregiver’s attempts to communicate to the person with dementia a sense of being equal to the caregiver while encouraging the resident’s ability to respond or reciprocate in the relationship. When these strategies led to the resident opening up, the resident would often tell stories about his/her past despite having communication difficulties. This process was supported when the caregiver had a good knowledge of the resident’s life story.

In their discussion of their findings, Ericsson and her colleagues observed that, at first glance, the caregiver setting aside time to develop a relationship with the resident without the resident first asking for this might be interpreted as the caregiver exerting power over the resident. This was described by Kitwood (1997) as a component of a malignant social psychology. They observed that providing care for a person with dementia is complex and the caregiver must be aware of their position of power. However, the caregiver's overtures are likely necessary to overcome the resident's relational deficits. Therefore the caregiver must have insight and be flexible to the needs of the resident. The core category of opening up was seen as consistent with Buber's reference to the "encounter" when one is open and available to the other (Buber, 1996; Ericsson et al., 2011). The resulting sense of security and trust experienced by the resident with dementia is essential to the development of the relationship between caregiver and resident (Ericsson et al., 2011)

The researchers identified two barriers to the use of RT. One was that it takes time to build relationships and time is at a premium in modern institutions. The second was that some caregivers are unwilling or unable to establish relationships with residents with dementia. For example, they do not have the relational or communication skills needed to achieve this (Ericsson et al., 2011).

Person-centered care and communication. The ability of caregivers to communicate with residents with dementia is an essential component of person-centered care and the promotion of personhood. The following is a summary of how communication interactions between caregivers and persons with dementia have been related to person-centered care, life history review and the development and maintenance of relationships between caregiver and personhood of the person with dementia.

Some of the interactions Kitwood included in positive person work were the caregiver's recognition of the person with dementia as a person and the use of negotiation and collaboration (Kitwood, 1997). The use of negotiation and collaboration are depended on the caregiver's ability to use effective communication strategies with the person with dementia. Referring to the caring behaviors identified by Pulsford and his colleagues (Pulsford et al., 2016), caregivers need effective communication skills to promote the resident's cognitive security through the expression of empathy and compassion. Caregivers must be able to communicate with the resident to share the resident's life story while interacting with the resident as a valued person (Egan et al, 2007; McKeown et al., 2010; Wolf, 2006). They also require appropriate communication skills to interact effectively with residents with varying levels of cognitive capacity to fulfill the three domains of relational interactions described by McGilton (McGilton, 2004). According to McGilton and Boscart (2006) relationships between caregivers and residents can only occur when the caregiver uses communication strategies that enhance the self-esteem and autonomy of the resident. In the study by McGilton and Boscart, care providers identified the resident's communication deficits as a major inhibitor to their developing a relationship with the resident. Conversely, they were enabled in developing relationships with residents when they could exchange information and stories easily. The ability of the caregiver to communicate warmth and understanding to a resident was an important finding of the study of Ericsson and her colleagues (Ericsson et al., 2011). These authors observed that an essential element of person-centered care is the ability of the caregiver to develop relationships with people with dementia through spending time and talking with the person.

The communication skills of the caregiver have been linked to almost all aspects of person-centered care. The definitions, theories and communication strategies related to

communication and persons with dementia will be addressed in the next section of this literature review.

Person-centered care and humanness. The dilemma of persons with dementia can be compared to that of disabled persons with mental retardation. Bogdan and Taylor are sociologists who conducted qualitative studies to explore the response of the non-disabled community to this population (Bogdan & Taylor, 1989; Taylor & Bogdan, 1989). These authors wrote that mental retardation is a social and cultural construct. This statement may also apply to persons with dementia. Both individuals with mental retardation and those with dementia display cognitive and physical disabilities that make them appear different from others, thus causing them to be labelled as deviant (Alzheimer Society of Canada, 2015; CAOT, 1998; Bogdan & Taylor, 1989; Kitwood, 1990, 1997). Taylor and Bogdan explained that the concept of deviance is created by society through the establishment and application of social rules: it is the infraction of these rules that cause persons to be interpreted as deviant (Taylor & Bogdan, 1989). This label results in these persons experiencing stigmatization and negative behaviors from others in their environment. As Taylor and Bogdan wrote, this label indicates a difference that discredits the person's moral character, resulting in their humiliation and frustration. The institutions and organizations designed to provide care for these individuals often promote behaviors that further alienate the person from the non-disabled community. The authors wrote that the labelling and stigmatizing of the mentally retarded may be inevitable in society (Taylor & Bogdan, 1989). These ideas are similar to Kitwood's writing about persons with dementia who experience the effects of what Kitwood named a malignant social psychology (Kitwood, 1990, 1997). As a result of their lost cognitive capacity, persons with dementia are viewed as being less valued than

non-disabled persons and as a result are stigmatized, invalidated, objectified, mocked, and disparaged by caregivers as well as by family members.

Despite the effects of mental retardation, some disabled individuals were observed to be loved and accepted by non-disabled individuals, such as parents and foster parents. As a result, these non-disabled persons were able to develop accepting relationships with the disabled person (Bogdan & Taylor, 1989). These relationships were described as long-standing and characterized by closeness and affection. In these relationships the deviant variable or mental retardation was not permitted to influence the relationship or the way the non-disabled person viewed and cared for the disabled person. Bogdan and Taylor used the term “humanness” to describe the qualities these non-disabled persons saw and promoted in the person with mental retardation. In defining humanness, the authors set out the four dimensions of the phenomenon: 1) attributing thinking to the other; 2) seeing individuality in the other; 3) viewing the other as reciprocating, and 4) defining social place for the other (Bogdan & Taylor, 1989).

The authors described how some non-disabled persons, such as parents or foster parents of mentally retarded individuals, believed that the disabled person could think and often communicated this thinking by nonverbal means such as eye movements or gestures. These interactions can be compared to the interactions of persons with severe dementia and their caregivers who learn to interpret the nonverbal communication of with persons with advanced dementia (Alzheimer Society of Canada, 2015; CAOT, 1998). Sometimes parents of disabled persons suggested they knew what the disabled person was thinking through intuition or by attempting to take on the role of the disabled person. The non-disabled identified the individuality of the disabled person by recognizing that person’s specific personality traits, likes and dislikes, feelings and motives, and by creating and maintaining the life history of the

disabled person. These understandings and interactions of the non-disabled persons with individuals with mental retardation correspond to elements of Kitwood's positive person work, including recognition and validation of the individual as a person,

Bogdan and Taylor (1989) found that non-disabled persons believed that the disabled person was able to contribute to the relationship and give something back to the other person. The non-disabled persons said they experienced companionship and new relationships as a result of their relationship with the person with mental retardation. They were made to feel special because they were contributing to the wellbeing of the disabled person. In addition, the non-disabled individuals created a place for the disabled person in their family or social circle. Disabled persons were understood to be family members and members of the larger social community, such as in church communities. The authors referred to this as the sequence of events resulting from the disabled person being adopted into a primary group and from there developing a social place in secondary groups.

Unlike Kitwood's writing about persons with dementia, most of the relationships and interactions explored by Bogdan and Taylor occurred in home and community settings. Kitwood wrote about interactions between paid caregivers and persons with dementia living in care facilities. However, there are commonalities between Kitwood's work and that of Bogdan and Taylor. Kitwood wrote, "To be a person is to live in a world where meanings are shared" (Kitwood, 1997, p. 87). He continued that interactions involve grasping the meaning of others and making a response that reflects an understanding of this meaning, reflecting the theory of symbolic interactionism. These ideas correspond to Bogdan and Taylor's description of the accepting relationships and interactions of the non-disabled and disabled persons described in their articles. When non-disabled individuals took on the role of the disabled person, attempted

to learn the meaning of the other's eye movements or hand gestures, or included the disabled person as member of their family or social group, they were taking on and sharing meanings with their disabled partners at a profound level. The social consequences and stigmatization of individuals with mental retardation and the concepts of humanness as set for by Bogdan and Taylor (Bogden & Taylor, 1989; Taylor & Bogden, 1989) help to inform our understanding of the dilemma of individuals with dementia and their need for relationship and recognition by caregivers and family members.

Person Centered Care and Social Role Valorization. Another set of concepts drawn from disability studies that can be compared to person-centered care and the interactions of health care aides and residents with dementia are together called *Social Role Valorization Theory* (SRV). SRV was developed in order to help people who are devalued in society to have more of the "good things in life". SRV came out of Wolfensberger's conceptual re-framing of normalization. The purpose of normalization in this context was to provide those who live with an intellectual disability a typical life. The word *valorisation* has been used to signify the attachment of value to people, and is taken from a Latin word, *valere*, meaning to accord value (Osburn, 2006; Race, Boxall, & Carson, 2005; Wolfensberger, 2013). In this case, Wolfensberger drew on the French translation of SRV and the relevant verb was *valoir* which means to accord values. It is useful to compare some aspects of SRV with the concepts associated with patient centered care.

This theory which was developed by Wolfensberger (Osburn, 2006; Wolfensberger, 2013) has to do with the enhancement of a disabled person's competencies and image in the eyes of the perceiver, thereby increasing the possibility of the disabled person having positive experiences with others and to receive the good things of life. These include being accorded

dignity, respect, acceptance and a sense of belonging (Osburn, 2006). However, devalued individuals or groups of people are more likely to be treated badly and have negative experiences. These experiences include: a) being perceived and interpreted as “deviant” due, for example, to physical or functional impairments; b) being rejected by their community, society, family and services; c) being seen in negative roles such as being subhuman, or a burden on society; d) being kept at a physical and social distance; e) having negative images, including negative language, associated with them, and f) being the object of abuse or violence. These experiences are similar to those described in Kitwood’s description of a malignant social psychology and the effects of the negative perceptions of family and caregivers upon older persons with dementia.

The channels through which role messages and expectancies are conveyed are: a) the physical environment, including the physical design and location of a setting associated with a person; b) the social context or the people associated with the person, including service staff; c) the activities expected or not expected of a person; d) the language used to directly address a person, or used indirectly about the person; and e) the personal appearance of the person, including their clothes and grooming (Race et al., 2005).

There are two categories of positive outcomes of SRV. One is the enhancement of the disabled person’s social image in the eyes of others and the second is the enhancement of the disabled person’s competencies. These can lead to the disabled person being valued by other individuals, by their primary, intermediate, and secondary social systems, and even by all of society (Osburn, 2006). Again, the positive outcome is to have more of the good things in life by holding valued social roles. Enhancing both image (how others perceive one) and competence

(the skills needed to successfully hold and perform valued roles) are the ways that one can get and keep valued social roles.

Action implications associated with SRV range from actions of individuals to those of social groups and society as a whole. Individual persons can work to enhance the social image and personal competencies of the disabled person by arranging physical and social conditions for a specific individual. Primary, intermediated and secondary social systems can enhance the social image and competencies of the disabled person by arranging physical and social conditions to that lead to the positive perception of the disabled person in that social system. Entire societies can arrange physical and social conditions throughout the society that are likely to enhance the perception of the entire group of disabled persons.

Osburn (2005) wrote that SRV is not prescriptive. The decisions about if and how SRV is to be implemented are determined by the higher order values of individuals or groups that transcend SRV and come from other sources. Osburn went on to write that these values, which are not always conscious, come from a variety of sources, such as a person's personal upbringing, family values, political and economic ideas, worldviews, and explicit religions. Therefore, what people do in their relationships with others, including disabled persons, depends on their values, assumptions and beliefs (Osburn, 2005).

In considering SRV and person-centered care, both are dependent on people being motivated to treat the vulnerable person well. Kitwood (1997) refers to this as positive person work. Proponents of SRV speak more widely of creating conditions in which the disabled person can thrive. What has application here to health care aides working with person with dementia is that the motivating factors for treating others well originate from the beliefs and values of each health care aide.

Person-centered care and the organizational structure of long-term care facilities. The previous studies have drawn attention to problems presented by the organizational environment in the implementation of person-centered care. These included staff shortages and the heavy workloads of caregivers. Hunter, Hadjistavropoulos, Thorpe, Lix, and Malloy (2016) conducted a study to explore the influence of individual and organizational factors on person-centered dementia care. Specifically, the researchers were investigating the association of personal and organizational–environmental characteristics with the self-reported behaviors of staff in long-term care facilities related to person-centered residential dementia care (PCRDC) (Hunter et al., 2016). They asked 109 long-term care staff (27 nurses, 44 nursing assistants and 41 other staff, including cleaning staff) from two rural Canadian long-term care centers to complete a series of surveys about their perceptions of the organizational support for person-centered care, beliefs about personhood in dementia and burnout. The authors used multiple linear regression analysis to test variable associations. The independent variables included employee characteristics (age, gender, occupation, and years of education), beliefs about personhood in dementia, and burnout. Other independent variables were three aspects of organizational support for person-centered care (the physical environment of residents, collaboration on care, and support from management). The dependent variables were five aspects of person-centered care: autonomy, personhood, knowing the person, comfort care, and support for relationships. The authors found that both organizational factors and personal characteristics were associated with some aspects of person-centered care. One of the findings was that organizational factors that supported empowerment of employees also supported PCRDC. These factors included the physical and social environment of the resident, the extent of collaboration on PCRDC, and supervisory or other organizational support of employees. The physical and social environment of the facility

was associated with the resident's autonomy. This suggested that the degree to which staff can facilitate resident autonomy depended on whether the resident can navigate the residence and have access to meaningful activities. Collaboration was the only environmental variable associated with four aspects of person-centered care: personhood, knowing the person, comfort care, and support for relationships. The authors suggested this indicated the need to change organizational processes rather than focusing only on the individual behaviors of staff. The only significant demographic factor was that female respondents reported higher levels of comfort care related to, for example, pain, agitation, sleep loss, and incontinence. Another finding was that the ability of employees to empathize with and respect residents regardless of disability supported the personhood aspect of PCRDC. Two aspects of burnout were associated with PCRDC. Personal accomplishment was positively associated with both personhood and burnout, suggesting that these workers would support the remaining accomplishments of residents even when these behaviors contributed to their own burnout. Emotional exhaustion was also positively associated with comfort care and support of resident's relationships. The authors observed that staff well-being may be an important factor in supporting person-centered care (Hunter et al., 2016).

Health care aides' attitudes and behaviors. In the study of caregiving in nursing homes by Schirm and her colleagues (2000), both licensed nurses and nursing assistants emphasized the importance of a caring attitude towards residents as an essential component to quality care. The concept of caring was associated with showing respect. Both groups agreed that this attitude was viewed as an innate quality rather than something that can be learned. They agreed that having a caring attitude made being a nursing assistant more than "just a job" (Schirm et al., 2000, p. 284).

Cruttenden (2006) commented that the relationships of front-line staff and their family members were often translated into the attitudes these staff members brought to the workplace. She observed that relationships based on the caring attitudes of front-line staff with family members supported these staff in providing dedicated service and developing strong relationships with both the residents and the resident's family members.

Coogle et al. (2007) studied job satisfaction and career commitment among nursing assistants providing care to residents with dementia. Data was collected from a state-wide dementia-specific training collaborative that included 12 hours of person-centered care training for all long-term care workers and a subsequent 8-hour train-the-trainer program for direct-care workers. A total of 930 subjects were selected for the study with 87.3% being either certified nursing aides or other direct service providers. The participants completed a paper-and-pencil demographic questionnaire and two career related questionnaires: the *Minnesota Satisfaction Questionnaire* and the *Career Commitment Measure*. The researchers found that current or previous informal caregiving experience was associated with higher levels of intrinsic job satisfaction for the caregivers. The authors postulated that this kind of intrinsic satisfaction may provide a kind of inoculation against the demoralization resulting from the "routine indignities of thankless jobs" (Coogle et al., 2007, p. 255). The authors observed that informal caregiving provided the caregiver with greater decision making latitude which led to a greater sense of confidence in managing behavioral problems. This increased confidence appeared to be associated with reduced burnout and greater job satisfaction. Another observation about the consequences of informal caregiving was that the caregivers frequently used language associated with family attachments to describe their relationships with residents and referred to family experience to describe their personal standard of good care. The caregivers believed they were

providing substitute or surrogate care and found this attachment empowering in their role as care providers.

However, these same workers had lower levels of career resiliency. The authors suggested this might be the result of the work environment not being conducive to the provision of same quality of care that the caregivers provided in informal caregiving. As well, paid caregivers were made to feel that affective caring was counterproductive to the organization's requirements for efficiency. An additional stressor was the blurring of boundaries when professional caregiving became a social relationship. When caregivers were asked to observe professional boundaries they felt conflicted since they found their meaning and purpose in providing surrogate care. In addition, nursing assistants frequently experienced high levels of stress in their personal lives which contributed to their inability to cope with job stressors. Another finding by Coogle and her colleagues was that previous training was associated with lower levels of intrinsic job satisfaction. They suggested the reason for this was caregivers being unable to implement the learning they have received. Other factors contributing to burnout were the unavailability of supplies, the relationships between workers and the social characteristics of the work environments. The authors recommended a commitment to the philosophy of person-centered care by all staff members in the environment and a professional commitment on the part of administration to create a new culture of care (Coogle et al., 2007).

Winzelberg, Williams, Preisser, Zimmerman and Sloane (2005) studied the relationship of nursing assistants' perceptions of the quality of life of residents in long-term care facilities and the nursing assistants' perception of their training. The researchers conducted a cross-sectional survey of 143 nursing assistants providing care to 335 residents in 38 residential care/assisted living facilities and nursing homes. They found an association between resident quality-of-life

ratings and the attitudes of nursing assistants regarding their training and person-centered care. In the discussion of their findings, the authors observed that person-centered care had been emphasized as important to the quality of life of residents with dementia. In this model of practice, care providers develop relationships with residents and try to meet each resident's individual cognitive and physical needs. The goals of person-centered care and quality-of-life perceptions are complementary, as they both focus on the resident's individuality and the need to avoid negative perceptions about the resident. Therefore, if nursing assistants perceive residents with dementia as having the capacity to engage in relationships and activities, they will consider that the resident's life has quality. As a result, the nursing assistants may be more likely to provide person-centered care. In addition, if nursing assistants have confidence in their training to assess and treat residents with dementia, they may believe that the resident's quality of life depends on the quality of their care (Winzelberg et al., 2005).

In a study about the importance of supervision in the retention of certified nursing assistants (CNAs) in the United States, Choi and Johantgen analyzed the data from the 2004 *National Nursing Home Survey* and the 2004 *National Nursing Assistant Survey* (Choi & Johantgen, 2012). They found that most CNAs were satisfied with their job, despite low pay and work stressors. Supportive supervision was a significant predictor of job satisfaction and intent to leave.

Chappell and Novak (1992) conducted a study in Manitoba in which they interviewed 245 nursing assistants from 26 nursing homes in Winnipeg, Manitoba. The purpose of the study was to test the buffering hypothesis that the negative effects of stressors, measured as burnout and perceived job stressors, can be moderated by social support at work and at home. Stressors were defined as any event in which environmental demands tax or exceed the adaptive resources

of the individual. Burnout was defined as attitudinal, emotional, and physical depletion. The hypothesis was not supported. Social support at work, specific training related to working with residents with dementia and support from family and friends provided some support to the nursing assistants. However, the authors found that the major steps to alleviating burden, burnout, and perceived stress were to decrease or change the workload and to provide rewards on the job.

The findings from a more recent study, this time conducted in the United States by Kennedy (2005), supported the findings of Chappell and Novak (1992). Kennedy conducted a descriptive, correlational study to compare levels of stress and burnout among three levels of nursing staff: registered nurses (RNs), licensed practical nurses (LPNs) and certified nursing assistants (CNAs). Seventy-two respondents completed two surveys: *The Nursing Stress Scale* and the *Maslach and Jackson Burnout Inventory*. She found that stress was strongly correlated to burnout. Registered nurses had the greatest degree of stress and burnout, CNAs reported a moderate degree level of stress and burnout and the LPNs reported the least. Inadequate preparation to meet the emotional needs of the clients and performing job duties were significant stressors.

Another study addressed inadequate training and burnout of nursing assistants in the United States. Castle and Ferguson-Rome (2015) explored the issue of the absenteeism of nursing assistants and its effects on the quality of care of residents. They studied the survey responses of 3,941 nursing homes in the United States. The quality indicators examined were the use of physical restraints, catheter use, pain management and pressure sores. In discussing the conceptual framework for the study, the authors observed that high absenteeism could be related to a number of stressors experienced by nursing assistants including: a) unpredictable work

assignments; b) frequent aggression and insults from residents; c) the sense of bereavement following the death of a resident under their care; d) low pay; e) belonging to a minority group; and f) personal challenges such as transportation difficulties, single parenthood and caring for other family members. Many of these problems arose because of the increased work burden experienced by these workers, with more work being done by fewer employees. Prolonged elevated absenteeism rates placed more burdens on other workers, with a probable negative effect on resident care. The results of the study showed that in the week previous to the survey, 9.2% of staff were absent from work. This absenteeism was related to a negative impact on the four quality indicators of the study. The authors noted that this level of absenteeism was higher than that of other industries. The authors observed that many of the stressors experienced by nursing assistants, such as low pay, conflict with co-workers and lack of promotion, may be both difficult and expensive for many nursing homes to change. However, supportive supervision and improved working relationships have been shown to reduce levels of staff turnover. Castle and Ferguson-Rome found the literature supported the use of consistent assignment as a means of improving cohesiveness among a team and helping staff to adhere to group norms while increasing cooperation. Secondly, training programs were recommended that would address the perception of many nursing assistants that they were unprepared to meet the care needs of residents, resulting in being absent from work or leaving work (Castle & Ferguson-Rome, 2015).

One of the most stressful factors impacting the work life of the health care aides has been identified as conflict with other staff, including fellow health care aides (Anderson, Toles, Corazzini, McDaniel, & Colon-Emeric, 2014). These authors conducted comparative, multiple case studies in four British nursing homes with 406 managers and staff. The data were analyzed using manifest content analysis to identify and explored patterns of relationships within and

between cases. The authors categorized two sets of “local interaction strategies” (LIS) as the “common pattern” and the “positive” pattern. Much of the conflict described by the health care aides in this study had to do with the use of the negative interaction strategies. These included refusing to help others, being critical, blaming others and “passing the buck” (Anderson et al., 2014, p. 6). Some of these interactions were attributed to other health care aides, but some were also identified in the interactions of health care aides with nurses. However, study findings suggested that when staff members used the set of positive local interaction strategies, they promoted inter-connections, information exchange, and diversity of cognitive schema in problem solving, all of which enabled them to provide better care. The authors recommended that facility sponsored efforts to increase an awareness of the value of positive interactions could heighten awareness of all levels of staff to the importance of these types of behaviors. Electronic media, such as teaching videos, could be used to enhance an awareness of positive interactions between staff members. Again, the greater involvement of nursing staff to act as role models and mentors in the use of positive staff interactions could have an impact on the overall culture of the care unit.

Health care aides and continuing education. A number of references have been made to the need of health care aides to receive continuing education following employment. Some studies identified the need for health care aides to receive continuing education to maintain professional competency and feel prepared to meet the needs of residents with dementia (Castle & Ferguson-Rome, 2015; Cummings et al., 2013; Kennedy, 2005). Cummings and her colleagues (2013) also recommended employers provide training for English as a second language. Extended orientation sessions were recommended to prepare the health care aide to meet the needs of residents while gaining a greater understanding of the role of nurses (Schirm et

al., 2000). Ongoing education for health care aides was also recommended to increase their ability to reduce and manage the agitated behaviors of residents (Cohen-Mansfield et al., 2007; Chrzescijanski et al., 2007; Livingston et al., 2014; McCallion et al., 1999). Adequate preparation to meet the complex needs of residents was also associated with increased work satisfaction (Winzelberg et al., 2005) while lack of educational preparation was linked to job stress (Kennedy, 2005) and absenteeism (Castle & Ferguson-Rome, 2015). Finally, Anderson and her colleagues recommended facility wide staff training programs to improve the interactions and working relationships between staff members to enhance their ability to meet the needs of nursing home residents.

Three training programs to increase the abilities of health care aides to function within the person-centered model of care are described in the literature. Thomson and Burke (1998) developed a three-hour training program aimed at sensitizing nursing assistants in a long-term care setting to the aging process and the experiences of the elderly. The study used a pre-test and post-test quantitative design. A total of 70 nursing assistants completed the pre-test with 34 completing the post-test questionnaire. Results of the study showed a significant improvement in the attitudes toward the elderly by the nursing assistants who attended the training sessions.

A second study (Passalacqua & Harwood, 2012) dealt with a communication skills intervention based on four elements of person-centered dementia care: Valuing people, Individualized care, Personal perspectives and Social environment (VIPS). The aim of the study was to test the feasibility of a series of four workshops built around VIPS that were intended to increase the person-centered communication, beliefs, and attitudes among paraprofessional dementia caregivers in a long-term facility. The researchers used a pre-test and post-test model to evaluate the effect of the intervention on communication strategies, caregiver burnout and other

variables associated with caregiving. The intervention was determined to be highly feasible based on the successful implementation of the four workshops, positive caregiver feedback, and positive outcome measures. Twenty-six caregivers attended at least two workshops and 18 of these attended all four workshops. Following the workshops there was a reduction in caregiver depersonalization of residents. Depersonalization was defined as treating a resident as a set of symptoms rather than as an individual. A reduction in depersonalization of residents and honoring them as individuals is one of the fundamental principles of person-centered dementia care. The researchers also reported the nursing assistants revealed an increase in both empathy and hope for those with dementia and reported using more concrete communication strategies. The researchers recommended the use of the VIPS training program as a useful tool to improve the quality of care provided by paraprofessionals in long-term care facilities (Passalacqua & Harwood, 2012).

The third training program for paraprofessional staff in the provision of person-centered care was described in a paper by Ruckdeschel and Van Haitsma (2004). This paper provided a background of person-centered care, caring for the caregiver and the emotions of caregivers providing care for residents with dementia as well as the emotions of these residents. The paper described a research-based workshop that promoted the skills of nursing home staff in recognizing and using emotional intelligence. In their discussion of person-centered care or resident-centered care, the writers pointed out the need to care for the whole person, not just his or her physical needs. In discussing the implementation of resident-centered care by paraprofessionals in long-term care facilities, the authors made the following points: a) principles of person-centered care had not been integrated adequately in the training of paraprofessionals; b) these workers needed to learn how to take care of their own feelings before they began to take

care of the residents' feelings; c) caregivers were called upon to develop relationships with residents as a means of understanding the resident and the resident's frequently illogical behaviors; d) the pervasive operation of a medical model in long-term care facilities and deficits in skills and motivation of front-line caregivers deterred the development of person-centered care; e) in this environment, non-professional caregivers were unlikely to believe that psychosocial care or person-centered care was within the parameters of their job; f) if these caregivers did adopt person-centered care practices, they had to incorporate these while efficiently meeting a wide range of physical care tasks; and g) these multiple demands could result in caregivers adopting an attitude of emotional detachment. The authors believed that information about psychosocial skills was not taught to paraprofessionals, such as certified nursing assistants (CNAs). Providing high quality care requires skill and empathy. From their review of the literature about emotions of caregivers and the emotions of persons with dementia, the authors formed the belief that CNAs could be taught specific skills such as behavior modification, empathy, and positive communication. The workshop they developed consisted of four sessions divided into two parts: "Taking Care of Your Feelings First" (Part I) and "Taking Care of Residents Feelings" (Part II). During the sessions, the participants were expected to attend to and share their emotional experiences that the authors proposed could have a lasting impact on both the participants' work and on their lives (Ruckdeschel & Van Haitsma, 2004).

The effectiveness of continuing education programs in long-term care was addressed in a literature review conducted by Canadian researchers in the care of the elderly (Aylward, Stolee, Keat, & Johncox, 2003). The researchers began their study with the following observations: a) the elderly currently residing in long-term care facilities have more complex needs since many continue to live longer in the community; b) learners encounter difficulties in the workplace

when they attempt to transfer new learning into practice; c) organizational and system factors can affect the sustained application of knowledge gained from continuing education programs and the adoption of innovations; d) the culture of long-term care is different from acute care because there is less emphasis and value on training and few incentives to encourage staff to change their practice; e) long-term care institutions are highly regulated and concerned about costs; f) frail older people are undervalued as well as their care providers; and g) continuing education initiatives have to accommodate a variety of abilities of staff, different education levels and a mix of learning styles.

To study the educational interventions, the researchers followed an evaluation system made up of three sets of factors. “Predisposing factors” referred to the materials used for the communication or dissemination of information that was designed to modify the recipients’ behavior (e.g. lectures, written information or video presentations). The second set of factors or “enabling factors” referred to conditions and resources within the environment that allowed or enabled an individual to implement new skills (e.g. modified work schedules, practice opportunities, or availability of treatment protocols or algorithms). The final “reinforcing factors” provided the individual with the cues or reminders to implement new skills or reinforced the use of new skills (e.g. peer support, advice, feedback).

The reviewers examined 48 studies. Only ten of the studies were in countries outside of the United States. Four studies took place in Canada, two in Britain, two in Sweden, and one each in facilities in Australia and South Africa. A major finding of the review was that 35 of the 48 studies only addressed predisposing factors. New knowledge was given staff without any enabling or reinforcing strategies to facilitate the transfer of new knowledge into behaviors in the workplace. The new knowledge was usually transferred in a training format with the length of

the programs ranging from 10 minutes to 56 one-hour seminars given in 28 two-hour sessions. The average length of all the training programs was approximately four hours. The major resident-care issues addressed in the studies were mental health behaviors, physical and chemical restraints and continence. Thirteen studies offered enabling strategies such as nursing assistants being given bedside opportunities for learning new methods for oral care. Five studies used interventions that included clinical instructions and reminders that reinforced the learning. Only six combined all three intervention types. Overall, there was almost no evidence of the effective sustained application of knowledge (Aylward et al., 2003).

Another study of nursing assistant training was conducted in the United States. It was carried out in response to a report to Congress about nurse staffing ratios in nursing homes (Nakhnikian, Wilner, Joslin, & Hurd, 2002). The report identified a number of staffing-relevant issues other than numbers/ratios that had an impact on quality of care. One of the most significant of these was nursing assistant training and education. The authors conducted a literature review and visited a number of sites, interviewing nursing assistants, researchers, nursing facility administrators, trade association staff, nursing assistant educators and supervisors and consumer advocates. The authors identified a number of concerns related to the training of nursing assistants. There was insufficient time to cover the material and have hands-on clinical training in pre-certificate classes. There was also a lack of supervision in the orientation of new employees to help them retain information and develop the critical thinking skills necessary to juggle competing demands. The greatest deterrent to the quality and effectiveness of training was the attitudes of top management who frequently failed to value front-line staff and their need for ongoing training. In addition, many nursing assistants passed their certification exams in either English or Spanish, but did not have the literacy skills they needed for the job. The authors

suggested employers encourage these staff members to attend English-as-a-Second Language classes. The authors also identified the need for both English-speaking and Spanish-speaking nursing assistants to learn to communicate with residents, families and supervisors. Finally, peer support groups and peer mentors were recommended to allow the nursing assistants to brainstorm and share ideas (Nakhnikian et al., 2002).

Ethical issues related to conducting research with health care aides. Health care aides can be considered a vulnerable research population. Romanchuk (2008) developed a categorization of the types of vulnerability including cognitive vulnerability, communicative vulnerability, deferential vulnerability and social vulnerability. Romanchuk defined social vulnerability as occurring when individuals have the power to consent but belong to an undervalued social group. When these categories of vulnerability are compared to the literature, health care aides are found to have cognitive strengths (Cranley et al., 2012) but to be susceptible to Romanchuk's other categories of vulnerability: communicative vulnerability, deferential vulnerability, and social vulnerability.

Communication and Persons with Dementia

Definitions of communication. Communication refers to the sharing of information by means of a system of language, signs and symbols. "Speech" refers to the motor production of sounds. Language refers to the symbol system by which sound is paired with meaning for a particular purpose (Bayles & Tomoeda, 2007; WHO, 2001).

Speech-language pathologists have identified three structural aspects to interpersonal messages: vocal, linguistic, and nonverbal. Vocal aspects included non-linguistic features such as voice quality and paralinguistic features such as pitch, loudness, duration, and silence. The nonverbal aspects included physical appearance, mannerisms, interpersonal distance as well as

gestures and facial expressions (Caris-Verhallen, Kerkstra, & Bensing, 1997; Ryan et al., 1986; WHO, 2001). In the most advanced stages of dementia, individuals rely on nonverbal communication such as pitch, loudness, facial expressions and body language to understand what is being said (Bayles & Tomoeda, 2007; Orange, 2001).

Bayles and Tomoeda (2007) emphasized the relationship between cognition and communication. They defined cognition as stored knowledge and the process for making and manipulating knowledge. Bayles and Tomeoda listed the stages of naming an object as perception, access to long-term memory, association, recognition, lexical retrieval, decision-making, motor planning and self-monitoring. Individuals with dementia have multiple cognitive deficits, including memory deficits. For this reason, communication is always affected by the neurological changes resulting in dementia (Bayles & Tomnoeda, 2007). Communication of persons with dementia can be understood as the outcome of pathology and body functioning within the context of the physical, social and attitudinal environments in which they live (WHO, 2001).

Wilcock (1998), an occupational therapy theorist, wrote that communicating through symbols is a basic human need and that human neurology has been developed to support this function. Communication is a determinant of health and a therapeutic medium (Bonder, 1994). Bonder identified communication as a means of healing through the expression of thoughts and feelings about unmet needs. Communication provides a way for the individual to exert choice and control that can result in desired changes and modifications to his/her physical, social, cultural or institutional environments (CAOT, 1997). The communication deficits of individuals with dementia frequently result in their not being able to express their choice of intervention or placement unless caregivers have the inclination and acquired skills to consult with them.

Sociologists Carpiac-Claver and Levy-Storms (2007) have studied communication as it relates to the communicative interactions of non-professional health care workers and older persons living in a long-term care facility. In this context, these researchers defined communication as a means of developing, defining and maintaining relationships between staff and residents. According to Carpiac-Claver and Levy-Storms, communication is characterized as a means of negotiation between individuals. They wrote of two purposes of speech: instrumental or task oriented speech and that which is affective or rapport building. They also referred to communication as having two components, content and the relational aspect. The content of speech refers to the verbal content of what is said while the relational aspect refers to what the authors called the nonverbal or emotional message. Both are important to successful communication with elders.

Carpiac-Claver and Levy-Storms videotaped interactions between 17 sets of nurses' aides and residents in two skilled facilities and six interactions of nurse's aides and residents of an assisted living facility. These interactions all occurred over mealtimes. Carpiac-Claver and Levy-Storms studied both the verbal and nonverbal communication of the sets of aides. They discovered four characteristics of affective communication. "Personal conversation" referred to conversations initiated by staff, including pleasantries such as saying "please" and "thank-you". This category of conversation also included laughter and talking about aspects of the personal life of the resident. "Addressing the resident" referred to using and reinforcing the resident's name and using terms of endearment such as, "honey", "sweetie", and "mama". "Checking in" occurred when the staff member asked how the older person was as well as inquiring about their comfort and wellbeing. These questions could relate specifically to questions about food preferences but also involved the worker making personal contact with the older person to

investigate their emotional state. The fourth type of affective communication was “emotional support and praise”. Praise was provided when the resident completed a task such as finishing a meal. Support, such as, “You can do it”, was offered to encourage participation in the task. In comparison, these researchers observed that instrumental speech was not usually accompanied by an affective component and therefore did not achieve the same level of emotional interaction as affective communication strategies (Carpiac-Claver & Levy-Storms, 2007).

Communication and dementia. Communication deficits are an inevitable consequence of the neurological changes associated with dementia (Alzheimer Society of Canada, 2015; Bayles & Tomoeda, 2007). Orange (2001), referring to the work of Bayles and Tomoeda (2007), described the communication deficits associated with each of the three stages of dementia resulting from Alzheimer’s disease. The person’s spoken and written language and communication skills gradually deteriorate from word finding problems and the use of stereotypic phrases, incomplete sentences and topic digression to increasing amnesia, reduction of content words, and repetition of words, ideas or utterances. In the late stage of dementia, the person may be mute or exhibit a continuous flow of words or sounds. They may eventually come to rely on changes in the communication partner’s voice pitch, syllable and word stress and emotional tone in order to understand their world, in addition to the partner’s nonverbal communication such as facial expression and touch (Orange, 2001). However, even in the later stages of the disease process, persons with dementia can relate stories of their lives (Cheston, 1996), express a range of normal emotions (Tappen & Williams, 1998) and should be given the opportunity to participate in care decisions (Goldsmith, 1998).

Speech accommodation theory. The integrity of the neurological processes supporting communication is only one factor contributing to effective communication between

conversational partners. Speech-language pathologists use the term psycholinguistics to refer to the combination of psychological and language processes that support the use and understanding of symbols. For example, this term refers to some concepts about the effect of the frequency of the recurrence of words. It also refers to the effects of grammatical classed of words and their use such as the use of some nouns as opposed to some verbs (or vice-versa) being easier to understand. The term encompasses other aspects of speech that promote use and understanding such as the use of more syllables as opposed to fewer syllables, personal relevance of speech, “imagability”, and other linguistic properties that effect both how speech is used and understood (J.B. Orange, personal communication, January 12, 2010).

Speech accommodation theory is specifically concerned with how social and psychological processes influence the linguistic and paralinguistic strategies adopted by individuals when speaking to each other as well as the effects of these strategies (Coupland, Coupland, Giles, & Henwood, 1988). These writers proposed that some communication strategies would be positively received by receivers while other strategies would result in negative evaluations and responses. Carrying these concepts further, Ryan et al. (1986) proposed that the quality of communication between individuals is an important precursor to psychological and physical health.

Three structural aspects to interpersonal messages have been identified, vocal, linguistic, and nonverbal (Ryan et al., 1986). Speech accommodation theory considers how these structural aspects of speech are modified according to the characteristics and needs of both communicators. Speech language theorists used the concepts of convergence (converging the style of speech to that of interlocutor) or divergence. For example, a caregiver’s speech may converge to a set of

negative stereotypes about an older person rather than the actual competence of the individual (Coupland et al., 1988; Ryan et al., 1986).

Ryan and colleagues (Ryan et al., 1986) identified four patterns of speech accommodation that are used by younger persons when they speak to non-institutionalized elderly. Over-accommodation due to physical/sensory handicaps occurs, for example, when younger persons speak more loudly than necessary to an older adult. While accommodation to actual sensory deficits is appropriate, overcompensation such as speaking too loudly or speaking in baby-talk is not. This is opposed to socially-insensitive non-accommodation or failure to accommodate to real sensory deficits. Dependency-related over-accommodation can be used to impose a power relationship with an older person with an older adult being classified as dependent. Inter-group over-accommodation occurs when older persons are treated with over-accommodation due to social category relationships. Categorization by physical appearance can be the result of a younger person's negative physical, social and psychological inferences about the older person that lead to over-accommodated speech. This behavior can be inadvertent and even empathetically driven. Age-related divergence can occur when young people use communication styles or linguistic modes of expression that make them appear different than the older adult, perhaps in an effort to maintain their identity. This strategy creates more social distance.

Ryan and colleagues suggested a number of factors that can predict a younger person using over-accommodated speech patterns. These included the younger person having little experience or knowledge about older people, having negative stereotypes about older people or a lack of intellectual sophistication. Ryan and her colleagues referred to this as the low "cognitive complexity" of the speaker. The situation is made worse when the older person is less able to

adapt his/her speech to the younger person's style. The result is a negatively-spiraling feedback loop that contributes to the communication predicament of the older adult, which will be discussed later. Older residents in long-term care facilities are most likely to experience inappropriate speech accommodation and the consequent communication predicament of aging. They represent a number of negative age cues such as limited functioning, visible frailty, use of function-limiting medications, high chronological age and sensory limitations (Ryan et al., 1986).

One of the more negative forms of speech accommodation is the patronizing communication directed toward residents of long-term care institutions (Coupland et al., 1988). Patronizing communication represents a type of speech accommodation used by caregivers which involves the use of baby-talk and "elderspeak" as well as the use of first names and/or over-accommodated psycholinguistic behaviors. It is characterized by exaggerated intonation, high pitch, less respectful forms of address such as "Honey", infantilizing content, use of the inclusive "we", over-parenting and demeaning behaviors.(Caporeal, 1981; La Tourette & Meeks, 2000).

Caporaal (1981) conducted a fieldwork observational study of nine nurses' aides to identify the characteristics of secondary baby-talk or the type of baby-talk directed toward seniors. Baby-talk is described as simplified speech with its own lexical items modified from adult speech. Its use is common to all cultures and across history. Some studies have been conducted with baby-talk used with small children but little with baby-talk directed to adults. This explorative study addressed the institutional environments in which speech occurred with the elderly to see if there was a link between caregiver/resident speech and the caregivers' perception of the residents.

The speech of nine caregivers was audiotaped at the noon meal. Caregivers also rated the care recipients on language use, eating behavior, sociability, alertness and likability. Caregiver speech was identified as either baby-talk, non-baby talk (speech directed to residents) or adult speech (speech directed to other caregivers). The analysis of the speech sample revealed that all caregivers used baby-talk with care receivers but they used more non-baby talk than baby-talk. There was no correlation between the use of baby-talk and care receivers' characteristics. Those listening to the tapes heard both the verbal content and the vocal features, such as vocal tone, of the speech sample components (Caporael, 1981).

Caporael then used the speech sample as a stimulus in two judgment studies to determine if baby-talk was paralinguistically different from other types of speech, if baby-talk directed to adults is different than baby-talk directed to children, and whether there were differences between non-baby talk and adult speech. Caporael (1981) observed no difference in the use of baby-talk with either children or older adults.

Kemper (1994) conducted a systematic evaluation of the psycholinguistic properties of a type of patronizing communication referred to as elderspeak. Language samples were obtained from ten volunteer service providers and ten caregivers speaking to young and older adults, some of whom were in the initial stages of dementia. Both service providers and caregivers used elderspeak that had similar characteristics to the patronizing speech described by Caporael. Simplified speech delivered at a slower rate was used with both community-dwelling and institutionalized elderly. Kemper stated that the results were surprising in that speech accommodation theory indicated that elderspeak resulted from age cues and negative stereotypes. Service partners and caregivers did not vary their speech for either group of elderly.

Caporaël (1981) observed that patronizing speech showed lack of respect and served three functions: a) over-parenting with the caregiver demonstrating a high level of caring with a low degree of respect; b) expressing disapproval; and c) not listening. All functions demonstrated the caregivers' low level of respect for the care recipient. Caporaël suggested patronizing behavior may be deemed more acceptable when it is directed to the cognitively impaired elderly with the nurse perceived as more nurturing and satisfied in these interactions. However Caporaël also observed the negative consequences of patronizing behaviors used with the elderly included reduced opportunities for the elderly to converse or to provide or obtain information as well as fewer opportunities to experience satisfaction from interactions.

Another concerning consequence of inappropriate speech accommodation discovered by Caporaël was a reduction in independent function. Negative behavioral consequences included increasing dependency with long-term care residents learning that increased dependency led to more social interaction with staff. Caporaël suggested dependency inducing styles could even be used in rehabilitation settings. The infantilization of institutionalized adults could be achieved by treating these adults as children and using the verbal and nonverbal forms of baby-talk and other patronizing speech. The resident might receive less respect from both caregivers and other residents who would be potential communication partners (Caporaël, 1981).

La Tourette and Meeks (2000) conducted a study to explore the evaluation of patronizing speech by two groups of elderly women. In their study, 38 female White nursing home residents and 62 White community-dwelling females viewed two audiotapes of a nurse about to give a flu shot to an elderly woman. In each audiotape, the script of the elderly woman remained the same. In one audiotape, however, the script required the actress playing the nurse to use patronizing speech while in the other vignette the actress used non-patronizing speech. In this study, non-

patronizing speech was defined as free of patronization, exaggerated intonation and other demeaning speech patterns associated with patronizing speech. The results showed that both groups of women preferred the non-patronizing speech and had more positive feelings about the competence and nurturance of the non-patronizing nurse. The cognitive status or length of nursing home stay did not have an effect on this finding.

Kemper and Harden (1999) attempted to identify the benefits of elderspeak. They developed three experiments to systematically study how the components of elderspeak, such as manipulations of prosody, affected older adults' comprehension. Their conclusions were that it is possible to develop a form of elderspeak that is useful to older adults and which does not result in negative self-assessments of communication competence or being perceived as insulting or patronizing. This form of elderspeak would be characterized with the use of semantic elaborations, such as the inclusion of more concepts, reduced syntax complexity and delivered with neutral prosody.

Communication theories of aging. Speech pathologists have developed two communication theories regarding the communication of caregivers with elderly persons. These are the *Communication Predicament of Aging (CPA)* and the *Communication Enhancement Model (CEM)*.

The CPA is a theory developed by Ryan and her colleagues who reviewed the literature about language and communication among the elderly (Ryan, Hummert, & Boich, 1995). These authors proposed that both young and old had lower expectations of the communication competencies of older individuals. They suggested these lowered expectations may result in conversational partners using communication behaviors such as oversimplified speech, baby-talk, or ignoring. An encounter with an older person might trigger recognition of cues related to

old age cues and stereotypic expectations about the older person's communication competence. The authors proposed this could lead to the younger person using modified speech behaviors including restricted topics, directive speech, simple or childlike speech, loud speech and exaggerated nonverbal communication behaviors. As a result of these behaviors, older persons might experience constrained opportunities for communication because the younger person felt unsatisfied talking with older adults, found no interesting conversational topics or avoided talking to older people. The older adult might avoid talking to younger people because they felt misunderstood and not respected. Younger individuals might reinforce stereotyped behaviors of older persons through adapting their talk to misconceptions about the needs of the older adult. The older person, in response to this adapted communication behavior, might come to feel dependent, quiet and cooperative, or alternatively, become complaining and demanding. Patronizing communication might be well intended but inevitably conveys a lack of respect.

The *Communication Enhancement Model* was first introduced by Levy-Storms who observed that training of front-line staff was a low priority in nursing homes (Levy-Storms, 2008). She commented that non-professional staff, such as nursing assistants and other front-line staff members, provided 90% of direct care in nursing homes but initiated little communication during their interactions with the older adult residents. Further, they displayed even less communication and communication of poorer quality with residents who had dementia than with residents who did not have dementia

In an elaboration of the CEM, Byrne and Orange (2005) referred to the *International Classification of Function* (ICF) (WHO, 2001) to illustrate that communication and communication deficits are the outcome of the interaction of body structures and function, pathology and contextual factors, including those internal and external to the individual. These

contextual factors were used to identify the communication needs of the older person in terms of his/her internal and inherent strengths and abilities as well as factors in the external environments such as family members and caregivers. (Orange et al., 1995; Ryan, Meredith, MacLean, & Orange, 1995) The CEM was therefore developed from ecological and health promotion perspectives and considered communication enhancement within multiple environments including social, cultural and physical (Wolf & Orange, 2009). The model was developed to apply to all types of caregivers. It emphasized the interaction between individuals and environments and determinants of health. The model assumed that communication impairments resulted from an imbalance between an individual's capacity and motivation and the expectations and opportunities in the environment. The model incorporated a feedback loop whereby the positive behaviors of each conversational partner helped to maintain the conversation through the recognitions of the needs and strengths of the other. This involved the development of individual assessment and intervention strategies that met the needs of the person with the speech deficit. The result was the increased self-confidence and social participation of the elder while optimizing his/her remaining cognitive and communicative abilities (Wolf & Orange, 2009). The positive behaviors of each conversational partner helped to maintain the conversation through the recognitions of the needs and strengths of the other. For caregivers communicating with persons with dementia, this model illustrated the need to interpret the individual with the speech deficit as an equal while developing individual assessment and intervention strategies to facilitate communication with him/her. These strategies could be used by both formal and informal caregivers to sustain the speech practices of the elder (Wolf & Orange, 2009).

Environmental influences and caregiver communication. Reflecting the recognition of the relationship between environmental factors and communication, speech

language theorists also considered the effects of the external and social environment upon communication. Ryan et al. (2005) referred to Tom Kitwood's concepts of personhood. Kitwood (1990) maintained that personhood was the basis of interactions with persons with dementia. He proposed five positive care interactions for supporting personhood with residents of long-term care facilities. These interactions included: a) recognition; b) negotiation; c) validation; d) collaboration; and e) facilitation. According to Kitwood, the person with dementia is the beneficiary of these positive strategies and is also capable of contributing to the discourse through these positive interactions. However, Kitwood recognized the time constraints of caregivers and emphasized that positive communication interactions could occur when caregivers used positive interactions during brief periods throughout all aspects of care. Providing care without these interactions could be reflective of a malignant social psychology (Kitwood, 1990, p. 49) that results in the disempowerment and possible abuse of persons with dementia.

The work of Adams and Gardiner (2005) demonstrated how a combination of personal and social factors could influence the communication of long-term care residents with dementia. They proposed that phenomena such as gender, ethnic background and socioeconomic status can work in combination with social factors to influence the self-concept and behaviors of individuals with dementia. They studied the communication dynamics that occurred in triads consisting of the person with dementia, the informal caregiver(s) and social or professional caregivers. They observed that either enabling or disabling communication could occur within these triads. Disabling dementia communication behaviors included interrupting the person with dementia with verbal or nonverbal behaviors, speaking on his/her behalf or reinterpreting what the person had said. Other disabling behaviors were: a) the use of complex and technical

language; b) talking out of earshot of the person with dementia; c) ignoring him/her; d) the use of ridicule; and e) failing to invite the person with dementia to the meeting. As a result, the person with dementia was less likely to assume a powerful position within the triad. Family caregivers would also assume less powerful positions than professionals. Adams and Gardiner recommended strategies to enhance the negotiating position of the person with dementia and his/her caregivers such as promoting equal participation and supporting the person with dementia to speak. Other strategies included being sensitive to the nonverbal cues of the person with dementia and providing a role model for how the informal caregiver could overcome poor communication strategies with the person with dementia and thus promote joint decision making.

Chrzescijanski, Moyle and Creedy (2007) referred to Kitwood (1997) and his observation that achieving person-centered care required a fundamental change in how caregivers viewed the person with dementia. The focus of care needed to be on the person and how he/she understood and experienced his/her world and needs. However, the authors found that staff members saw dementia-related behavior as a problem to be overcome in getting their work done instead of an opportunity to provide a specialized service to residents. These writers found that factors that influenced staff attitudes included the overall philosophy of the nursing home facility, societal attitudes towards aging and older people and the personal attributes of the staff. They proposed that positive attitudes might help care staff see a person with dementia through more perceptive and sensitive eyes, thus reducing the use of psychotropic medication and other forms of restraint.

Communication and caregiving. The communicative interactions between caregivers and residents of long-term care facilities has been identified as a major factor in the quality of life experienced by residents (Caris-Verhallen et al., 1997; Carpiac-Claver & Levy-Storms, 2007; Levy-Storms, 2008). As previously stated, effective communication strategies can result in

residents with dementia experiencing greater self-confidence and functional ability while maintaining cognitive and communicative abilities (Wolf & Orange, 2009). Communication is also seen as a means of developing and maintaining relationships between caregivers and care recipients (Carpiac-Claver & Levy-Storms; 2007; Levy-Storms, 2008, McGilton, 2004). As previously mentioned, the two aspects of the communication between caregivers and residents are the content of speech and the relational aspect. There are usually two purposes for this communication: task completion and affective or rapport building (Caris-Verhallen et al., 1997; Carpiac-Claver & Levy-Storms, 2007).

While instrumental communication relies on the use of words, affective communication frequently relies on nonverbal communication signals such as tone of voice, gestures and facial expressions, and the use of personal distance (Caris-Verhallen et al., 1997; Ryan et al., 1986; WHO, 2001). Magia, Cohen, and Gomberg (2002) proposed that individuals in the later stages of dementia, like preverbal infants, may be especially receptive to the nonverbal signals of others. Therefore the manner in which caregivers interact with individuals with dementia can have significant influence on the mood states of these care recipients.

The verbal and nonverbal communication patterns of caregivers in the institutional environment can influence the level of dependence behaviors of residents. Baltes et al. (1994) conducted a study to determine the effect of a staff training program on the occurrence of dependence-supportive and independence-supportive behaviors of staff interacting with elderly residents of long-term care institutions. They conducted a pre- and post-test observational study involving 27 staff members from two nursing homes and a geriatric facility in Berlin. The staff members were observed interacting with a total of 106 residents with a mean age of 83.2 years. The staff participants, including both professionally trained and non-professionally trained staff,

were divided into an experimental and control group. The experimental group was given a ten-session training program which was not provided to the control group. Both groups were observed prior to and following the training program. The study revealed that, in both the control and study groups, staff promoted dependent more than the independent behaviors of residents. However, the study also demonstrated the benefit of staff training because fewer dependency-supportive staff behaviors were identified in the study group that had received training. There were also somewhat fewer dependent behaviors of the residents following the training programs.

Levy-Storms (2008) referred to residents with cognitive and communication impairments and their need for therapeutic communication. She defined therapeutic communication as verbal and nonverbal communication that helps these residents overcome stress, anxiety, fear or other distressing emotional experiences. She observed that nursing assistants initiated little communication during interactions with the older adult residents and even less with residents with dementia. However, Levy-Storms concluded that these were the very residents who require a higher level of purposeful therapeutic communication. Not surprisingly, nursing assistants identified communication skills as one of their most important learning needs.

Browne and Braun (2008) expressed concerns that immigrant workers who have English as a second language and come from cultures that are different from that of their care recipients lack the communication skills or cultural experience to meet the emotional needs of frail elderly residents. They felt this was particularly true for end-of-life care. However, in the face of labor shortages in long-term care, high workloads and staff turnover, the authors suggested that administrators were likely to continue hiring these immigrant women.

Although there are examples in the literature of health care workers using positive communication strategies with residents with dementia or undertaking to learn how to improve

these strategies, there is also evidence of contrary cases. McGilton (2004) referred to studies that demonstrated the communication used by staff with residents with dementia was primarily instrumental, with little affective content. “Staff got their work done with minimal interactions with their residents and little concern for how they were feeling” (McGilton, 2004, p. 74). Magia et al. (2002) suggested that the heavy burden of caregiving of staff working with residents with dementia can result in these staff members demonstrating critical and hostile behavior. The authors observed that these workers may express negative emotions in the presence of residents with dementia because they believe these residents have reduced emotional sensitivity. Caris-Verhallen et al. (1997) conducted a review of studies about the role of communication in the provision of care for older persons. They found examples of staff using patronizing speech and over-accommodation to exert control over these older persons. These interaction strategies served to constrain open communication with residents. Residents were left to go on with morning care, which they could not do, with minimal staff-resident interaction. Keeping in mind that residents in the later stages of dementia are potentially more susceptible to negative verbal and nonverbal communication (Magia et al., 2002), it can be assumed that these contrary cases have devastating effects on the sense of personhood and wellbeing of these residents.

This review of the literature demonstrated that the quality of life as well as communication capacity of residents with dementia can be positively or negatively affected by a combination of contextual factors that are internal or external to the resident. The communication abilities of persons with dementia are always compromised by the neural deterioration resulting from a brain disease. As well, residents have few opportunities to interact with others during each day, resulting in their having less confidence and practice in using their remaining ability to speak and interact with others. Most of their interactions are with health care aides and occur

either during the provision of care or in the social interactions on the nursing unit. The effect of these interactions can either promote the retention of the cognitive, functional, and communication abilities of residents or result in these residents becoming dependent, passive and unwilling to engage in interactions with others.

Concepts of Personhood and the Person with Dementia

In this section the development of the terms, “person” and “personhood” will be presented as these terms apply to individuals with dementia. These concepts of personhood were used to sensitize my understanding and perceptions of the data during the coding processes.

One of the most significant contributors to the development of the concept of personhood and the person with dementia was Dr. Tom Kitwood. Kitwood wrote about the need to recognize and preserve the personhood of individuals with dementia, including those residing in care facilities. It was Kitwood who first used terms such as “transcendence”, the “absolute self”, and “embodiment” in describing the personhood of persons with dementia (Kitwood, 1990, 1997, 1998). He also identified the applicability of Buber’s concepts about the “I-Thou” relationship to the concepts of personhood and dementia (Buber, 1996). The following is a review of ten concepts of personhood. They were developed during a study of the perception of the personhood of persons with dementia by their adult children (Wolf, 2006). These concepts were drawn from Kitwood’s work as well as from the literature of a number of disciplines including ethics, sociology, psychology, theology, and the clinical disciplines of nursing, speech and language pathology, and occupational therapy (Wolf, 2006).

Personhood and the absolute self. This first concept of personhood and the person with dementia deals with the innate essence and uniquely human quality of the person with dementia (Kitwood, 1998; Spike, 2000). Kitwood proposed that the person has absolute value (Kitwood,

1998; Kitwood & Bredin, 1992a2). Bioethicist Berghmans (1998) proposed that the person before dementia and the person afterwards are the same person with the same values and beliefs. Jeffrey Spike, an ethicist, described the person with dementia as a distorted and diminished survivor, but agreed with Berghman's view that this person retained the same beliefs and values as that person had before the onset of the illness. Another ethicist, Stephen Post (2000), stated the person is not diminished by dementia. This is the same view of the person with dementia that is supported by the Manitoba Alzheimer Society in their document, *A Strategy for Alzheimer Disease and Related Dementias in Manitoba* (Manitoba Alzheimer Society, 2002).

Personhood and transcendence. This concept also deals with the unique qualities and essence of the person, but this time as they are expressed through relationships with others, with the creator, and through occupations (Egan & DeLaat, 1997). Kitwood and Bredin (1992) described the person as "transcendent", with an essential inner spirit. Buber proposed that we experience the potential of the person through our senses and therefore give the other person meaning. Buber also believed that the perception of God's spirit within the person contributed to how the individual was seen as a person. McCurdy wrote that all persons have the capacity to transcend their physical selves. He continued that human beings all have the characteristic of spirituality or the capacity for relationships to whatever or whoever gives meaning, purpose or direction to a life (McCurdy, 1998)

Personhood and embodiment. The personhood concept of embodiment is based on the understanding that the person exists in a physical body that in turn is located in a specific physical and historical context. The psychiatrist and ethicist, Hughes (2001), proposed a situated-embodied-agent (SEA) view of the person with dementia. In this view, the person is embodied in a historical context of space and time. Following the onset of dementia, the person

remains a person even if he/she has lost the ability to recall the past. The sociologist, Jenkins (1996), pointed out that because a person exists in a physical body, the gender, race, and ethnicity of the body play a critical role in determining the development of the person. Kitwood explained that, because the person exists in a body, psychological events are brain events and are dependent both on how the brain developed but also on the effects of pathology. Kitwood wrote of the “pathology of personhood” (Kitwood, 1997).

Personhood and the existence of mind. This concept refers to the need for a person to be capable of thinking and knowing through the agency of the mind. Kant was the first philosopher to consider the attributes of the mind and the development of the “self”. He proposed that the mind was linked to the self, with the development of the self being a result of the individual’s interaction with the external world as well as through self-reflection (Banerjee, 1974). This understanding is reflected in the work of George Herbert Mead and Herbert Blumer in their development of the theoretical tradition of symbolic interactionism (Blumer, 1964, Speziale & Carpenter, 2007; Jeon, 2007; Strauss, 1965). Dennett (1976) stated that personhood demanded that a person be seen as a rational being able to understand the consequences of his/her actions and behaviors. Ethicists Buchanan and Brock (1990) linked the changed decision making abilities of the person with dementia to the need for substitute decision makers. However, they believed that, since the mind of the person with dementia was so changed, there was no need for these decision makers to observe the individuals previous preferences. This, however, is contrary to the ideas of other writers, such as Atchely (1989).

Personhood and retaining one’s personal history. This concept is based on the understanding that a person is someone who is perceived by others as capable of recalling and representing his/her past. The psychologist Neisser (1998) and the philosopher Schechtman

(2005) both agreed that memory theory alone did not explain the distinctive character of a person but that persons retain an unconscious understanding of themselves that is consistent with the person they were before amnesia or dementia. Although the individual may not be able to recall specific events in their past life, they retain the inner knowledge of self that determines if he/she will respond to present events with feelings such as guilt, shame, or pride, as they might have done in the past. Atchely (1989) wrote of an inner continuity of an individual whereby the individual retained their previous ideas, temperament and preferences. Therefore the evidence of one's representing his/her personal history appears to depend on an inner knowledge of self that has been developed throughout the lifespan as well as the recall of specific events.

Personhood and language. The function of language contributes to the recognition of the personhood of an individual because of its critical importance in enabling a person to express his/her wants and needs to others as well as asserting himself/herself as a being. This idea was proposed by speech-language pathologists (Bryan & Maxim, 1996). The concept was also supported by the ethicist Dennett (1976), who asserted that a person is one who can communicate verbally, and Mead (1965), who saw language as essential in the process of normal human development. Although speech pathologists have studied the apparent loss of an awareness of self through loss of language skills, others such as Small, Geldart, Gutman, and Clarke-Scott (1998) and Tappen, Williams, Fishman, and Toughy (1999) have observed that persons with severe dementia still referred to themselves with the first-person indexical, "I". These authors surmised that the way an individual is treated in their environment may influence how the person acts and speaks. They refer to the concepts of self that were proposed by Sabat and Harre (1992) in which the concept of the self may be changed according to the response of others in the individual's environment. This concept supports the theories of speech

accommodation (Orange, 2001) which predict that individuals with dementia will either retreat from communicative interactions or make an effort to enter into conversations with others, depending on the attending and communicative behaviors of the others in their environment.

Personhood and personality. The concept of personhood and personality deals with the personality theories developed by Jung, as well as the personality theories proposed by Kolanowski and Whall (1996). Reber (1995), in a dictionary of psychology, lists three types of personality theories: type theories, trait theories, and psychoanalytic theories. The same source states that these three types of theories established personality as a legitimate construct that influences behavior. More recently, personality psychologists have agreed on a fundamental taxonomy of personality traits known as the five-factor model. These traits are: a) neuroticism; b) extraversion; c) openness; d) agreeableness; and d) conscientiousness (Kolanowski & Whall, 1996; Siegler, Dawson & Welsh, 1994). Kitwood (1997) suggested that instead of using personality inventories, the personality of the individual with dementia should be addressed in terms of the person continuing to be “meaning maker” and someone who can experience and appreciate events as they happen.

Personhood and dependency on the regard of others. Kitwood’s definition of personhood (1997) is the following: “It is a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect, and trust” (Kitwood, 1997, p.8). Kitwood referred to a “malignant social psychology”, whereby caregivers and family members, acting out of kindness and good intentions, reflected what Kitwood called the “malignancy of our cultural experience” (Kitwood, 1997, p. 46). As a result, these caregivers and others used negative interactions with persons with dementia that included: a) treachery; b) disempowerment; c) infantilization; d) intimidation; e) labelling; f)

stigmatization; g) outpacing; h) invalidation; and i) objectification. Kitwood later added the following behaviors to this list: a) ignoring; b) imposition; c) withholding; d) accusation; e) disrupting; f) mockery; and g) disparagement (Kitwood, 1998). However, Kitwood developed the model of person-centered care built on the assumption that persons with dementia continue to be valued persons. He proposed “positive person work” that included: a) recognition or acknowledging the person with dementia through verbal interactions such as using his/her name or by nonverbal interactions such as direct eye contact; b) negotiation or the person with dementia being consulted about his/her preferences, desires or needs rather than being conformed by the assumptions of others; c) collaboration or working together as equals; d) play or the exercise of spontaneity; and e) validation or the acknowledgement of the experience of the other.

Personhood and the person being seen to continue in a personal narrative. This concept is based on the work of life course theorists such as Elder (1977, 1998), Elder, Shanahan and Colerick, Clipp (1994) and Hareven (1982) who believed that an individual experienced the story of his/her life in the context of the physical, social and cultural world in which they lived. These theorists proposed that the status and experience attributed to individuals in their later years was molded by their cumulative life history and specific aspects of their personal life. Hughes (2001) expressed the belief that the person with dementia experienced changes due to the dementia but remained essentially the same person. The ethicist Harrison (1993) accepted that the personhood of the individual with dementia was affected by the changes in cognition, communication, role, and self-image. She continued by writing that the individual must be viewed in the terms of his/her life story and also within their current context if their personhood is to be preserved.

Personhood and occupation. This concept of personhood is based on the occupational therapy theories of enabling occupation and occupational performance (CAOT, 1997; Law et al., 1996; Townsend & Polatajko, 2013). According to these theories, occupations are any activities of everyday life “that are named, organized and given value and meaning by individuals and a culture. Occupation is everything that people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their community (productivity)” (CAOT, 1997, p.34). As represented in the *Canadian Model of Occupational Performance (CMOP)*, the person, with a spiritual core and physical, cognitive, and affective components, performs occupations within their physical, social, cultural and institutional environments. The person is understood to be an active agent in the environment, capable of choosing, organizing, and performing meaningful tasks and activities. Occupational performance is the outcome of the interaction of the person, their environment and the demands of the occupation (Law et al., 1996). Occupational therapy theorists make the connection between an individual’s ability and “competency” to perform activities and the achievement of personal meaning and identity. The occupational therapy theorist, Christiansen (1999), considered the consequences for the individual when he/she exhibits impairments in his/her ability to perform occupations. He observed that such impairments of occupational performance resulted in the individual no longer being perceived as being able to fulfill societal roles.

Although persons with dementia are limited in their abilities to perform most occupations, many remain able to participate in occupations that meet each individual’s unique goals and interests and that are meaningful to the individual. Meaningful occupations are those that allow an individual to fulfill a goal that is personally important (Salvatori, 1999). For

example, some residents with dementia residing in long-term care facilities remain able to participate in meaningful occupations such as leisure and self-care activities. When a resident is supported in performing self-care activities, he/she experiences greater autonomy and dignity. When a resident with dementia participates in leisure activities that represent past interests, he/she is able to retain some of his/her past personal history. The result of participating in these activities is that the person experiences greater satisfaction with their lives (Palatajko, 2014).

In the study about personhood and persons with dementia (Wolf, 2006), the adult children of persons with dementia most frequently described the personhood of their parent in terms of the parents past occupations such as a farmer or businessman, homemaker, volunteer, or parent.

In summary, individuals with dementia may not be recognized or treated as persons by caregivers. Instead, these caregivers may objectify the resident and use behaviors that infantilize, demean, and dismiss the resident. These ten concepts of personhood are drawn from a range of literature including the writings of philosophers, ethicists, theologians, as well as clinical practice theorists from psychology, nursing, speech language pathology, and occupational therapy. They provide a variety of ways of interpreting and explaining the individual with dementia as a person. One of the most powerful of these themes may be personhood and the dependency upon the regard of others. Once the individual is recognized as a person by caregivers, their interactions with the resident may reflect other themes of personhood.

Summary

This review of the literature has covered the topics related to health care aides working in long-term care as well as the literature about communication and dementia. Finally, it has been used to present ten concepts of personhood. The literature about health care aides and

communication and dementia was referred to in the development of the study proposal. As well, the questions in the interview guide for the individual interviews with health care aides were drawn from this literature. The concepts of personhood were used as a source of theoretical sensitivity in data analysis.

The literature about health care aides working in long-term care included topics such as a description of health care aides, their essential competencies and training, their place within the organizational structure, and their role in delivering person-centered care. Other topics related to health care aides were an exploration of their attitudes and behaviors, their continuing education needs and the ethical issues related to conducting research with health care aides.

The literature about communication and dementia addressed topics such as the definitions of communication, communication and dementia, communication theories, environmental influences on caregiver communication and communication and caregiving.

Despite this extensive range of topics, at least one significant gap has been identified in the literature. Of the nearly fifty studies represented in this literature review, most were quantitative studies dealing with topics such as the function of health care aides within the organizational structure, the effect of training programs in reducing resident agitation or descriptions of the health care aides' patterns of work. The majority of these studies used methods such as literature reviews, observations of health care aides functioning within their role, surveys, pre-test and post-test studies and even one placebo-controlled study. Only ten of the studies involved researchers interacting with health care aides in individual interviews or focus groups. These studies addressed issues such as work stressors, staff relationships, the role of health care aides in organizational change or methods to reduce resident agitation. The study by McGilton and Boscart was the only study that explored the experiences of health care aides

interacting with residents with dementia. However, this study also included interviews with family members. What was not addressed in the literature was an exploration of the lived experience of health care aides as they interacted with and provided care to residents with dementia. This study about the communication interactions of health care aides with these individuals will be devoted exclusively to exploring the experience of health care aides. As such, the findings of this study will be used to address this concerning gap in the current literature about caregivers and residents with dementia in long-term care facilities.

Chapter Three: Theoretical Perspectives

The theoretical areas represented in this study are symbolic interactionism and grounded theory. Each will be described briefly along with an explanation of their application in this study.

The choice of grounded theory for this study was guided by the research questions as well as the lack of evidence from previous studies on this topic. Although a body of literature existed concerning the use of speech accommodation by caregivers of older persons, including those with dementia (Baltes et al., 1994; Caporael, 1981; Caporael et al., 1983; Coupland et al., 1988; Kemper, 1994; Kemper & Harden, 1999; Orange et al., 1995; Ryan et al., 2005; Ryan et al., 1986), there were no previous studies about the lived experience of health care aides as they interacted with care recipients with dementia. One of the purposes of grounded theory is to develop new theory from a specific substantive area as opposed to exploring concepts and theory from previous works (Glaser, 1978; Speziale & Carpenter, 2007).

The research questions led to an exploration of how elements of the environment influenced the behaviors of health care aides as they provided care for long term care residents. According to Blumer (1969), each individual's environment is made up of objects to which the individual attributes meanings that are unique to that person. The way that individuals act towards or respond to objects is determined by the meanings they give to these objects. Blumer (1969) stated that people may live side by side yet be living in different worlds because of the unique meanings they give to the objects in their environments. In order to understand each person's unique interpretation of the world, one must identify their world of objects and the meanings they attribute to these objects (Blumer, 1969).

This study is a grounded theory study designed to develop a mid-range theory that can describe and explain the communicative interactions of HCAs with residents in long term care with dementia. The philosophical underpinnings of grounded theory research are the interpretive tradition of symbolic interactionism (Blumer, 1969; Strauss, 1965; Speziale & Carpenter, 2007). In this section, the concepts of symbolic interactionism will be presented and then discussed as they might apply to the interaction of health care aides with long-term care residents with dementia. The section will end with a review of literature about grounded theory research, including a brief discussion of where grounded theory fits in the development of qualitative research (Denzin & Lincoln, 2005; Speziale & Carpenter, 2007).

Symbolic Interactionism

According to Jeon (2004), symbolic interactionism provides an interpretive perspective in research as opposed to a traditional, positivistic quantitative study. It results in an approach to research from the individual's experience of meaning making as he/she interacts with others in his/her environment. The theoretical tradition of symbolic interactionism was developed by Herbert Blumer and George Herbert Mead (Blumer, 1969; Jeon, 2004; Speziale & Carpenter, 2007; Strauss, 1965; Taylor & Bogdan, 1998).

George Herbert Mead taught philosophy at the University of Chicago. As a pragmatist, he was concerned with a philosophy that proposed humans go through a continual process of adaptation in a constantly changing social world. As well as making significant contributions to modern social psychological thought, his writings have contributed to the development of grounded theory research. Although many of the conceptual underpinnings of symbolic interactionism were developed by Mead, it was Blumer who coined the name (Strauss, 1965).

According to Strauss, Mead was influenced by Darwin's ideas about evolution. Mead believed that the mind and intelligence evolved as a result of human interaction with others through time and that the self and human society developed in the same manner. The human evolved in the physical world as an active agent. According to Mead, the self consists of subjective "I" that is natural and spontaneous, without external interference, but that the objective "me" sees "self" as a reflection of what others see and is therefore influenced by these others. Mead stated that the "I" and "me" aspects of the individual were constantly in communication with each other. This resulted in the human's ability to self-reflect and in the process takes on the role of the "other". As a result of these processes, individuals are able to communicate with each other through the use of symbols. He proposed that the human self develops through the ability of the individual to take on the attitudes of the group to which he/she belongs. This results in social habits which in themselves evolve into the structure of society. The use of language and symbols are important in this process because humans use and develop these symbols to understand the meaning and implications of the behaviors of others while communicating their own meaning in return. Thinking occurs in the interactions of the "I" and "me" selves, while intelligence is developed as a result of communication with others. However, no-one can really understand what is happening in the mind of another except through that other person's vocal and physical behavior (Strauss, 1965).

Blumer (1969) extended the ideas of Mead. He concluded that human beings act toward things on the basis of the meanings that the things have for them. He identified "things" - or objects - as everything that the human being may note in his/her world, including physical objects, other human beings, categories of human beings such as friends and enemies, institutions, such as hospitals, and guiding ideals, such as honesty. Blumer believed that the

meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing. Therefore, according to Blumer, meanings are derived through an interpretive internalized process that involves the individual interacting with himself/herself to categorize and modify the meaning of the thing according to the external situation. Using this process, the individual determines what action he/she should take. Later Blumer observed that all human conduct is the outcome of social interaction through the use of symbols or gestures.

Mead described a three-part nature of the meaning of gestures: what the person to whom it is made is to do, what the person who is making the gesture is planning to do, and finally the action that they will perform together. In the process of reaching this mutual understanding, both persons must consider the role or identity of the other person. Mead and Blumer believed that taking the role of the other is a critical element of symbolic interactionism (Blumer, 1969).

Blumer identified four central conceptions of symbolic interactionism as they apply to human “group life and social interaction” (Blumer, 1969, p. 50). These conceptions were: a) people act on the basis of the meaning objects have for them; b) people interact by making gestures to each other and interpreting these gestures; c) social acts of either individuals or groups of individuals result from a process of observing the gestures of others, interpreting the gestures, and assessing the situation; and d) the complex interactions through which social institutions are developed are in a constant process of evolution and are not static (Blumer, 1969).

Symbolic interactionism and research. Blumer felt strongly that research be conducted to explore the real or empirical world without pre-formed concepts or theories. In what he called, “methodological principles of empirical science” (Blumer, 1969, p. 21), he aimed to provide an approach that would result in verifiable observations about individuals and groups

in society. He stated that empirical science implies a world that can be seen and studied. He argued that although the world of reality exists in the images and thoughts of those who study it, that these images and thoughts should not be codified in theories that remove the researcher from actual experience in the lived world. Blumer describes the empirical world as difficult to understand and having the capacity to “resist and talk back” (Blumer, 1969; p. 22) to the researcher. He referred to the obdurate nature of the empirical world. In this case, “obdurate” means hardened or not easily moved, stubborn and not giving up easily (Guralnik & Friend, 1966). Blumer wrote that the researcher must strive against this obdurate nature with all modes of scientific inquiry, not just those of the physical sciences. He argued that research methods should be chosen that match the aspect of the empirical world being studied and that the empirical world and not a preconceived set of concepts or theories should be the ultimate test of the validity of the work. He extended his understanding of the empirical world to include the study of the social life of human beings, including what they experience as individuals or collectively. He believed that all levels of human activity and social interaction can be explored and that the empirical world is the world of everyday experience (Blumer, 1969).

Blumer (1969) also wrote about the use of concepts in research. He explained that concepts play a central role in research and are the significant element in how the researcher comes to understand the world. Concepts are used for developing the research problem as well as grouping data and developing the relationships between the data and are key elements in interpreting the findings.

According to Blumer’s methodology, the researcher must work to: 1) establish an understanding or “prior picture” (Blumer, 1969, p. 24) of the aspect of the empirical world being studied; 2) ask questions of the empirical world and convert these questions into problems; 3)

determine the data needed and the means of collecting it; 4) determine the relations between the data; and 5) interpret the findings (Blumer, 1969). Ultimately, the researcher must determine if these findings are confirmed in the empirical world. Blumer advocated intense examination or what he called inspection of the empirical world to identify the elements to be used in analysis. In his mind, scientific analysis requires two things, a clear identification of both the analytical elements and the relationship between these elements. He used language that was later applied to grounded theory research (Blumer 1969; Glaser, 1978; Jeon, 2004; Strauss & Corbin, 1998) by stating that the researcher's observations of the empirical world must be grounded in the evidence.

Communication and symbolic interactionism. Communication, or the act of an individual exchanging thoughts and ideas with others, is understood within a range of epistemological and ontological assumptions and related definitions (Balyes & Tomoeda, 2007; Blumer, 1969; Byrne & Orange, 2005; Jeon, 2004; Strauss, 1965; WHO, 2001). Both Mead and Blumer (Blumer, 1969; Jeon, 2004; Mead, 1934; Strauss, 1965) considered communication in terms of symbolic interactionism. They proposed that human beings act toward things or objects on the basis of the meanings these things have for them. The meanings associated with objects and words result from a process of group action and consensus. An individual develops an understanding of the meaning of words through life-long and constant interaction with others and with one's self. Mead attributed the development of one's mind and thinking processes to use of symbols in a process of continuous self-interaction. An individual's awareness of "self" and personal identity is achieved through a process of constant self-interaction and use of symbols to interpret others' perceptions of the individual. The individual then modifies and develops his/her

understanding of self to reflect this interpretation and accommodate his/her behaviors to reflect this understanding (Blumer, 1969; Mead, 1934; Strauss, 1965).

Mead referred to the interaction between individuals as a social process. He described communication as the act of an individual making a declaration through the use of symbols or words that have common meaning to another individual or to a whole group of individuals. In this process, the individual assumes the attitude of the other so that a common understanding between all participants is achieved. Mead and Blumer believed that human action is not some form of automatic response to environmental stimuli or social structures but reflects the attitudes of individuals toward each other (Blumer, 1969; Mead, 1934; Strauss, 1965).

Speech accommodation theory or the study of the social implications of language reflects Mead and Blumer's ideas about individuals relating to each other through communication. Accommodated speech such as elderspeak and secondary baby-talk can reflect the attitudes of younger caregivers to older persons with dementia. This type of speech may be used to express endearment but is usually demeaning. Through these speech patterns, caregivers demonstrate how they see the resident as incapable and even child-like. The resident receives this message and responds by becoming more dependent, more communicatively incompetent and generally less able to function.

The problem presented by caregivers who have English as a second language is that they may not understand the literal and implied meanings of English words that have been developed through lifetimes of social interaction involving English speakers imbued with the culture of, in this case, Western Canada. Therefore they are less able to interpret the meaning being conveyed through the speech of residents, supervisors, or family members. Conversely, the English speakers may not always understand the implied meaning of what is said to them by immigrants

because they are not familiar with the culture of the other person and the latter's lifelong development of meanings in another physical, social, and political context.

This study will use grounded theory methodology. The next section on grounded theory will reveal that many of Mead's and Blumer's ideas and beliefs expressed in symbolic interactionism contributed to the development of this methodology. Some of these include the explanation of the relationship of the development of the meanings of objects through social interaction and the need for close inspection of the empirical world to locate data for analysis that in turn is grounded in empirical observation.

Grounded Theory

Description of grounded theory as a research method. Grounded theory is associated with the tradition of symbolic interactionism. It is a general, interpretive method of qualitative research that is based on the systematic generation of theory from empirical data that are systematically acquired, analyzed and conceptualized (Strauss & Corbin, 1998).

Specziale and Carpenter (2007) list five characteristics of grounded theory methodology:

1. The conceptual framework of grounded theory is generation of theory from the data rather than from previous studies.
2. The researcher attempts to discover a dominant process in the social scene rather than describe the unit under investigation.
3. The researcher compares all data with all other data.
4. The researcher may modify data collection according to the advancing theory, that is, the researcher drops false leads or asks more penetrating questions as needed.

5. The researcher examines data as they arrive and begins to code, categorize, conceptualize, and write the first few thoughts concerning the research report almost from the beginning of the study.

McCallin (2003) writes there are two core characteristics of grounded theory. The first is theory is achieved through the constant comparison of empirically-based data. The second core characteristic is that the researcher uses theoretical sampling and samples situations rather than people. According to McCallin, grounded theory has five basic premises. The first premise is that analysis is basically pragmatic, with the researcher finding guidelines in the literature for a study but ultimately using his/her creativity and ingenuity during analysis. The second premise is that the aim of qualitative analysis is to generate new concepts and theories. The third premise is that theories should be “grounded” in empirical reality while the fourth premise is that the researcher is open- minded and willing to put aside or critically evaluate preconceived ideas. The final premise is that participants cannot be predicted at the beginning of the study since participant selection is influenced by the theoretical sensitivity acquired by the researcher through process of data analysis.

Morse (2001) states the distinguishing characteristics of grounded theory are that it focuses on a process with identifiable stages and phases, it uses gerunds (Glaser, 1978) indicating action and change and has a core variable or category (Strauss & Corbin, 1998), a basic social process or basic social psychological process (Glaser, 1978; Speziale & Carpenter 2007) that ties the stages and phases together. Although grounded theory is abstract, it makes the “syntheses of descriptive data readily apparent through its concepts and relational statements” (Morse, 2001, p. 2). Strauss and Corbin (1998) go on to say that once concepts are related

through statements of relationship into an explanatory framework, the analysis moves beyond conceptual ordering to a theory that can explain or predict events.

There are different types of theory. Substantive theory is developed from the inquiry of the observed or empirical world. An example would be a study about the effect of patronizing speech on older persons involved the observation of caregiver interactions with residents of a nursing home (Caporeal, 1981; Kemper, 1994). Formal theory is developed from a more abstract and conceptual area of inquiry. For example, a formal theory about communication could address the more abstract concepts of personhood and communication. As opposed to grand theories which are broad in scope but may not have operationally defined concepts, grounded theory is midrange theory which can be empirically tested and operationalized in the empirical world (Speziale & Carpenter, 2007; Strauss & Corbin, 1998).

Location of grounded theory in the history of qualitative research. According to Denzin and Lincoln (2005), there have been eight moments in the development of qualitative research. They name these moments as follows: 1) traditional; 2) modernist; 3) blurred genres; 4) crises of representation and legitimation; 5) post-modern; 6) post-experimental; 7) the methodologically contested present; and 8) fractured future.

The representation of these eight moments is presented in Table 4.

Table 4.
Eight Moments in Qualitative Research

Name	Dates of Moment	Description of Moment
Traditional	1900-1950	-Interest in observing the “Other” -Researcher as aloof observer
Modernist	1950-1970	-Social realism, naturalism & slice-of-life ethnographies still valued -Efforts to formalize qualitative methods -Researchers drawn to qualitative practises that gave voice to society’s underclass
Blurred genres	1970-1986	-Research and writing more reflexive -Attention to gender, race, and class -Triple crises of representation, legitimation, and Praxis
Crises of representation	1986-1990	-Writings more reflexive; called into question the issues of gender, class and race
Post-modern	1990-1995	-Experimental designs and new ethnographies -Different ways of representing the “Other” -Concept of “aloof observer” gone -More participatory, activist oriented research -Grand theories replaced by theories for specific situations
Post-experimental	1995-2000	-Experimental forms of qualitative writing; blurred lines between science and humanities; novel ways of expressing lived experience
Methodologically contested present	2000-2004	- era of conflict, tension, and retrenchment
Fractured future		-confrontation of methodological backlash associated with “Bush” science and evidence-based social movement

Note: Denzin and Lincoln, 2005, pp14-20

Annells(1997) wrote that grounded theory was initially developed by Barney Glaser and Anslem Strauss in the second moment of the development of qualitative research or the modernist phase. Annells writes that this phase was characterized by a formalization of qualitative methods and a belief that inquiry can solve social problems. During this phase, Glaser and Strauss worked to generate a grounded theory method that would be more useful than theory generated from prior assumptions. Their thinking appears to reflect the post-positive paradigm with recognition of a reality that existed to be uncovered but which could never be perfectly apprehended. Annells writes that during the third moment, the thinking of Strauss and Corbin diverged from that of Glaser who came to represent the classical method of grounded theory. Strauss identified with the American school of pragmatism (Annells, 1996). This was a philosophical stance whereby research was seen to be driven by “anticipated consequences of deliberate, self-controlled conduct” (Cherryholmes, 1992, p. 13). It also involved a rejection of post-positivism, critical realism and modified objectivism which remained associated with Glaser’s classical approach to grounded theory

A comparison of the grounded theory methods of Glaser and Strauss

Paradigms of inquiry and grounded theory. The following is a brief review of the paradigms of inquiry that have developed from the modernist research moment until the present and will be used to begin a study of the methods of grounded theory associated with Glaser and Strauss

A paradigm is a world view or a basic belief system. Guba and Lincoln wrote that paradigms are based on three questions. The first of these is the ontological question or what is the form and nature of reality. The second question is the epistemological question or what is the nature of the relationship between the knower (or would-be knower) and what is known. The

third question is the methodological question or how can the inquirer go about finding whatever he or she believes to be known (Guba & Lincoln, 1994, 2005). These authors compared and contrasted four paradigms, positivism, post-positivism, critical theory, and constructionism. In the positivist paradigm, the researcher believes there is a reality that is known. The researcher has a dualist relationship to this reality. Reality is understood in terms of the observer and the thing being studied. The methodological approach in this paradigm is experimental, with the researcher using manipulation of the conditions of the research and then verifying the results. This paradigm is used chiefly in quantitative research. Referring to the post-positivistic paradigm, reality is understood to be only partially or imperfectly known. The epistemological approach is that of a modified dualist. The understanding is that the findings are probably true. The methodology is modified experimentation with an attempt to falsifying rather than verify a hypothesis. The ontological approach within the critical theories paradigm is one of historical realism. The researcher believes in a virtual reality that is shaped by social, economic, political, cultural, ethnic, or gender values and becomes crystalized over time. The epistemological approach is transactional and subjectivist; the findings are value mediated. The methodological approach is dialectical or dialogic. Finally, in the constructivism paradigm the researcher understands that reality is relative and is locally constructed for a specific situation. Again the epistemological approach is transactional and subjectivist and the methodological approach is hermeneutical or dialectical (Guba & Lincoln, 1994, 2005).

Although grounded theory was developed through the mutual efforts of two sociologists, Barney Glaser and Anselm Strauss (Annells, 1997; Melia, 1996), the two came to different ways of understanding and implementing this research method. Annells (1997) writes that Glaser's method was based on looking at a substantive area with the aim of generating an inductive

grounded theory in an area of general interest. Glaser believed that the Basic Problem (BP), the basic questions, and the Basic Social Process (BSP) emerged from the data. However, according to Annells, the product of this method is a hypothesis that must later be verified through surveys or experimental research.

Glaser (1978) set out specific requirements for theory. According to him, theory must have “grab” and attract people’s interest in a way that they would remember and apply in practice. In Glaser’s view, theory must fit the data and not be forced to fit preconceived ideas or theories. Theories must “work” or be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive or formal inquiry. As well, theory is modifiable and can be changed to reflect new data. Theories must be relevant to the core variable of the data (Glaser, 1978; Hall & Callery, 2001). Glaser also spoke of the transcendence of theory which occurs when a new theory transcends a variety of previous works and integrates them into a theory of larger scope (Glaser, 1978).

Strauss and Corbin focused on a phenomenon rather than a substantive area. They defined theory as, “a set of well-developed concepts related through statements of relationship, which together constitutes an integrated framework that can be used to explain or predict phenomena” (Strauss & Corbin, 1998p. 15). In their work they refer to the verb “theorizing” as the act of constructing an explanatory scheme from data that systematically integrates various concepts through statements of relationship. Strauss and Corbin’s method leads to grounded questions (instead of a grounded problem) as well as the development and testing of a grounded hypothesis regarding a social process (Annells, 1997; Melia, 1996).

The basic social process. Speziale and Carpenter (2007) stated that the identification of a dominant process in the social scene is one of the main characteristics of grounded theory

research. Glaser explained that this dominant or *Basic Social Process* (BSP) involves most of the action observed in an area and relates most of the categories with each other. A BSP serves to integrate the categories of data with each other in the formulation of theory (Glaser, 1978). Alternatively, Strauss and Corbin (1998) refer to a central category. They list the criteria for choosing a central category as follows: a) all other coding categories must relate to it; b) it must appear frequently in the data; c) the name or phrase used to identify the category should be sufficiently abstract that it could be applied to other substantive areas and lead to wider application of the theory; d) refining of the category achieves greater depth and explanatory power; and e) the category is able to explain variation, contradiction and alternative cases (Strauss & Corbin, 1998, p. 147).

Theoretical sensitivity. Glaser (1978) stated that the researcher is to come into the study with few predetermined ideas, especially those related to pre-determined hypotheses. The researcher does not filter his/her observations through existing theory or preconceived ideas but remains open to what the data will reveal. However, the researcher can be sensitized by the literature from the field of study or from other fields, such as psychology, public health, economics or politics. Glaser continued that the researcher's professional orientation provides a background with "guidelines and reference points which the researcher uses to deductively formulate questions which may then elicit data that leads to inductive concepts being formulated later" (Glaser, 1978, pp. 37-38).

Grounded theory and data collection. The source of data for grounded theory studies is from interviews and field observations (Glaser, 1978; Strauss & Corbin, 1994, 1998). At the beginning of the study, there are no limits set on the number of interviews or data sources. Sampling is therefore considered as theoretical rather than purposive. Morse stated that the

criterion of good data is that data are continuous over time, experiential, readily conceptualized and present adequate variety (Morse, 2001).

Theoretical sampling. The following is a discussion of the process of theoretical sampling used in the grounded theory methodology of Strauss and Corbin (1998). These authors defined theoretical sampling as data gathering that is directed by the concepts that evolve during data analysis and is based on making comparisons between these concepts. Its purpose is to explore how concepts vary in terms of dimensional range or properties. The guiding questions that direct theoretical sampling change over time throughout the stages of theory development. The researcher is attempting to vary the conditions by which more properties and dimensions of concepts and categories can be discovered. The researcher goes to places, people or events that will maximize the opportunities to discover these variations in terms of their properties or dimensions (Strauss & Corbin, 1998, p. 201). The researcher samples from incidents, events, and happenings but not people per se. Each event sampled builds from and adds to data previously gathered and analyzed.

Sampling occurs throughout the process of theory development. Initial sampling questions include: a) what site or group is to be studied; b) what type of data is to be used, such as interview or observational data; and c) what number of sites will be sampled as determined by their accessibility and the resources and time of the researcher?

One sampling procedure can be the use of an interview guide which has been developed from the literature, the researcher's experience or preliminary fieldwork. However, the questions in this guide are provisional and may be discarded as the study proceeds. The problem presented by rigid adherence to an interview guide is that participants' responses will be limited to provide only the information requested, thus restricting the range of responses of the participants.

Sampling procedures vary according to the type of analysis. For example, sampling for open coding is done to create as many concepts and categories as possible. Data are compared by comparative analysis. Questions arise from this stage of analysis that lead to further data gathering. Strauss and Corbin provided the following advice for researchers: a) look for sites that can provide data that expands the properties and dimensions of the identified concepts; b) proceed systematically, going from person or place on the list to another, sampling on the basis of convenience; c) be aware that differences in the data may appear unexpectedly; and d) return to data already collected, reorganizing them to be relevant to the developing theory.

Strauss and Corbin refer to the sampling for axial coding as relational or variational sampling. The researcher samples incidents or events that identify a variation in the data or illustrate a dimensional range or variation of a concept or of the relationship between concepts. The authors state that this sampling depends on what sources of data are available and that the researcher should be prepared to make the most of what is available.

Sampling for selective coding or discriminate sampling is done with the goal to integrate the categories or relationships among concepts and to fill in any categories that are incomplete. This type of sampling is very deliberate, with the researcher choosing the sources of data that will maximize comparative analysis. The researcher may have to return to former sites, documents, or persons or go to new sources of data. Validation of the relationships and the developing theory is built into each step of analysis, with comparisons of products of analysis with actual data.

Grounded theory and data analysis. The following is a description of the analytic processes developed by Strauss and Corbin (1998). They state that the analytic processes in grounded theory provide the logic underlying the identification of concepts and their relationship to each other. The use of analytic tools stimulates the inductive reasoning process and leads to finding what is in the data while discarding preconceived assumptions. This process leads to the identification of concepts and their labels, or conceptualizing the data, the grouping of concepts into categories, and the discovery of properties and dimensions of these categories. In the grounded theory mode of Strauss and Corbin, the questions that stimulate this process include, who, what, when, where (Strauss & Corbin, 1998). According to Strauss and Corbin (1998), analysis proceeds in four stages: open coding, axial coding and selective coding and validating the theory.

The first stage of data analysis is open coding which is also referred to as Level I coding, or substantive coding. This stage involves conceptualizing the data to abstract representations of incidents, events, or happenings. Each event or incident is named or labeled so that it can be categorized according to similarities and differences (Strauss & Corbin, 1998).

During the second stage of analysis or axial coding, concepts or phenomena are placed into categories and subcategories according to their properties. During this process, categories are related to their subcategories along the lines of their properties or dimensions. Strauss and Corbin refer to using a paradigm which is an analytical tool used to integrate the conditions (who, what, when, where, why) and structure or conditional context in which a category is situated with the process or the sequence of actions and interactions related to the phenomenon. Terms used for this process come from ordinary life: structure, process, conditions, actions and interactions and consequences of the actions. Structure, for example, refers to the conditional

context in which a phenomenon is situated or the means through which it is manifested. Structure addresses the questions of who, when, why, where, how, and with what consequences?

Conditions relate to structure and are events or happenings that influence a phenomenon and are either causal or intervening conditions. The latter often arise out of unexpected events (Creswell, 2013; Strauss & Corbin, 1998). Process refers to the actions and interactions pertaining to a phenomenon over time. Actions or interactions may be altered in response to changes in conditions or may influence structural conditions. There may be sub-processes as there are sub-categories with actions and interactions being given properties and dimensions in the same manner as are categories (Strauss & Corbin, 1998).

The third stage of analysis or selective coding requires the further integration of the data into a theoretical scheme and the location of the central category or the core variable (Creswell, 2013; Speziale & Carpenter, 2007; Strauss & Corbin, 1998). This stage results in a further abstraction of data into relationships that more clearly define the properties and dimensions of categories as well as the structure and processes related to the activity from which the theoretical construct is drawn. Strauss and Corbin (1998) stress the importance of theory being built from abstract relationships that rise beyond a list of themes.

Validating the theory is the final stage of analysis and involves reviewing the theory for internal consistency and logic and identifying any underdeveloped categories. This process requires standing back from the theory and returning to the data to confirm its logic and consistency. The central category, for example, must continue to relate to most or all of the concepts in the categories and subcategories. If the analysis has left questions, represented by underdeveloped categories, the analyst must return to the raw data or find new data to address this gap. The final theoretical scheme should explain most of the activity, structure, actions and

interactions related to the social process being studied (Speziale & Carpenter, 2007; Strauss & Corbin, 1998).

Grounded theory and rigor. In qualitative research, the concepts of reliability and validity correspond to the concepts of credibility or truth value, dependability or the stability of the data over time, confirmability or the ability to follow the researcher's decision making and transferability or the ability to use study findings in another context (Krefting, 1990; Speziale & Carpenter, 2007).

Some of the concepts used to describe the rigor of grounded theory studies include Glaser's (1978) criteria for rigor, including "fit" or how well the core category relates to the salient social problem (Hall & Callery, 2001). Glaser also used the terms "relevance" and "work" to refer to the degree to which the core category represents the substantive data. As well, the central category or core variable must have characteristics that are relevant to the data and serve to integrate a theory that is dense and saturated in its relationship to other categories (Glaser, 1978; Hall & Callery, 2001).

Strauss and Corbin use the criterion of plausibility to refer to how well the research process and development of theory fit reality and are useful (Hall & Callery, 2001). They also refer to conceptual density when referring to the number of categories related to conditions and consequences, and the dimensions associated with these categories.

Credibility compares to truth value in qualitative research as related to internal validity in quantitative studies. In a qualitative study truth value is determined by how well the findings represent the multiple realities that are perceived and understood by the participants in the context of the study (Krefting, 1990; Sandelowski, 1986).

Transferability compares to the concept of external validity in quantitative research or the degree to which research findings can be applied to populations outside of the study (Krefting, 1990; Portney & Watkins, 1993). Krefting associates this concept with those of fittingness or transferability as applied to qualitative studies. These criteria are met when study findings fit into contexts outside of the research situation (Krefting, 1990).

In qualitative studies, dependability refers to whether another researcher would come to similar conclusions if they replicated the study with similar subjects and study context (Krefting, 1990; Sandelowski, 1986). Glaser (1978) and Strauss and Corbin (1998) use the term “reproducibility” to apply to how well another researcher should be able to develop the same relationship of concepts if they followed the same rules for data gathering and analysis as the original researcher.

Confirmability corresponds to the concept of auditability, or the strategy of an external auditor attempting to follow the sequence of decision making and progression of events that led to the findings of the study (Krefting, 1990). Sandelowski (1986) stated that auditability is achieved when the researcher leaves a clear decision trail from the beginning of a study to its end. Burns (1989) wrote that the researcher must observe descriptive vividness about the site, the subjects, the experience of collecting the data and the thinking of the researcher during the process.

Summary

Symbolic interactionism has been explained in this chapter, including its relationship to communication. The basic characteristics of grounded theory methodology have also been presented as well as a discussion of the difference between the Classical or Glaserian mode of grounded theory as opposed to the reformulated version of Strauss and Corbin.

Chapter Four: Methods and Procedures

The methods and procedures used for this study are presented in this chapter. These will include: 1) recruitment procedures; 2) data collection processes including a discussion of theoretical sampling; 3) data analysis processes; 4) ethical considerations; 5) strategies to enhance the rigor and credibility of the study; and 6) a discussion of processes to implement knowledge translation.

The Researcher as Research Instrument

I have been led to this research study by a number of factors. I grew up in an extended family with many elderly relatives. I believe this led to my interest in working with older people. As a young occupational therapist, I worked in one of the first facilities in Canada to develop evidence-based approaches to the care of the institutionalized elderly. My personal experience with illness gave me an understanding of feeling undervalued. I believe it is a combination of these experiences that led to my passion for improving the lives of persons with dementia. I have been particularly concerned that persons with dementia continue to communicate and be respected as the persons they once were. At the end of my career as a clinician with some limited experience in research, I wanted to make a contribution to the field of study about persons with dementia and their communication interactions. I realized that by exploring the experiences of health care aides who have the most interactions with person with dementia in long-term care, I might be able to discover information that would contribute to the quality of life of the persons they care for. Sandelowski (1986) has written that qualitative inquiry “may be viewed as blending scientific rules and artistic imagination”. Occupational therapy has been described as both an art and a science. This research project has allowed me to explore both of these areas of human experience.

Methodology

The methodology used in this study was the mode of grounded theory developed by Strauss and Corbin (1998). The choice of grounded theory methodology was based on the desire to explore the social process of health care aides interacting with residents with dementia as they provided care for these residents (Speziale & Carpenter, 2007; Strauss & Corbin, 1998). The rationale for choosing this mode of grounded theory was that the constructivist paradigm of inquiry associated with this mode is compatible with my perception of reality as being created and specific to local situations. This perception has been supported by my experience as an occupational therapist conducting interviews with clients with a range of disabilities. Secondly, this mode situates the researcher within the work. Again, this placement of the researcher as being an active agent in the research process reflects my experience as a therapist working with clients. The analytical processes developed by Strauss and Corbin provide a useful framework for data analysis. Finally, this method leads to the development of theory that has practical application.

Previous studies about communication interactions of health care aides and residents with dementia involved researchers observing and analyzing the communication behaviors of caregivers and the effect of these behaviors upon residents with dementia. Studies about health care aides in long term care were almost entirely concerned with the role of the health care aide in the organizational structure, the observation of health care aides at work or communicating with care recipients or the response of the health care aide to training programs. No study had been conducted exclusively about the experience of health care aides with residents with dementia and their interpretation of these residents. As much as the development of this study was informed by this previous work, an underlying assumption was that concepts related to the

interaction of health care aides with residents with dementia had not been identified. A second assumption was that the relationships of such concepts were not fully understood or were conceptually underdeveloped (Strauss & Corbin, 1998). This study involved interviewing health care aides and exploring the lived experience of these care providers as they cared for and interacted with care recipients. These health care aides were recognized as the experts and sources of data for the study (Speziale & Carpenter, 2007). The purpose of this study was to develop a midrange theory to explain and predict the health care aides' perceptions of residents with dementia and how these perceptions influenced their verbal and nonverbal communications with these residents.

Recruitment procedures

The sample for this study was gathered using nonprobability, theoretical, and purposive sampling techniques (Portnoy & Watkins, 1993; Strauss & Corbin, 1998; Thorne, 2008). The goal of these combined sampling strategies was to achieve a sample from settings and groups of people who were potentially representative of the population of health care aides employed in long-term care facilities in Winnipeg. The sample was gathered from sites that differed in characteristics. These differences included facilities being either faith-based or secular in their orientation or being managed by a private board as opposed to being managed by the regional health authority.

The sample itself was comprised of health care aides employed in long-term care facilities in Winnipeg. The inclusion criteria for health care aides were: a) the ability to speak and understand English; b) being employed in a long-term care facility in Winnipeg; c) having provided care to residents with dementia at the time of data collection or within the year prior to data collection; and d) being willing to volunteer and consent to participate in the study. Since

the individual interviews were conducted during working hours, the only exclusion criterion was the inability of a health care aide to leave the unit for the interview.

Once research ethics board (REB) approval was obtained (Appendix O), health care aides were recruited from four long-term care facilities in Winnipeg which were identified as Facility A, Facility B, Facility C, and Facility D. The provincial funding and regulation for all four facilities was managed through the Winnipeg Regional Health Authority.

Facility A was a 387-bed facility providing a range of services, including stroke rehabilitation, long-term care, palliative care, chronic care, and a day hospital. The health care aides interviewed for this study worked on either of the two special needs units for residents with dementia. An interdisciplinary team provided the resident care on each unit. The facility was managed by an executive team reporting to a board of directors. The mission statement of the facility emphasized nurturing the life of the resident as well as efforts to fundraise to enhance services to patients and residents.

Facility B was an 88-bed personal care home founded by a Christian denomination. The facility's mission statement said the facility provided programs for primarily elderly residents that were based on Christian values with the aim of preserving the personal dignity of the resident while supporting the resident's physical, social, emotional, and spiritual needs.

Facility C was a faith-based 100-bed facility that opened in 2000. It was an accredited long-term care facility within a larger health care complex. The mission statement identified that the facility was a leader in providing specialized and long-term care to meet the needs of an aging population according to the denomination's Christian tradition of ethical and spiritual values. These values included compassion, innovation and excellence and reflected the legacy of the denomination's facility founders.

Facility D was a 487-bed facility providing a range of services for older adults including inpatient, outpatient and day hospital services. The inpatient services included a Special Care Unit or secure unit for individuals with dementia and related disorders. The mission statement for Facility D stated the facility served adults with complex needs who required rehabilitation or specialized care for long-term care concerns. It referred to its role that involved service delivery, education, research, and the promotion of health and wellbeing throughout the community.

The process for being granted research access and establishing initial contact with health care aides as potential participants varied between facilities. In the case of Facility A, I sent *The Letter for Long-term Facilities* (Appendix C) and the document, *Information about the Study* (Appendix D) to the Chief Nursing Officer (CNO). I was advised to complete the facilities' *Research Access Application* and send it to the Manager of the Research Center. Once research access was granted, the CNO arranged that I attend a meeting with the unit managers of the long-term care units. At this meeting, I referred to the *Script for Meeting with Managers* (Appendix F). Following the meeting, the Director of Residential Care gave me permission to contact the Unit Manager of one of the Special Care Units. This manager arranged two meetings at which I could meet with health care aides on his/her unit during scheduled unit meetings. I brought the *Consent Form for Participation in an Individual Interview* (Appendix A) and the *Consent Form for Participation in a Group Interview* (Appendix B), copies of the *Poster* (Appendix G) as well as copies of the document *Information about the Study*. When meeting with the health care aides, I referred to the *Script for Health Care Aides* (Appendix E). I explained the study and went through the *Consent Form for Participation in an Individual Interview*, emphasizing the voluntary nature of participation in the study and the confidentiality of all information provided during the interviews. I also explained that a group interview was the

second stage of data collection and I then referred to the consent form for the group interview. I left copies of both consent forms and *Information about the Study*. I was given permission to put up the posters about the study on the unit. Two health care aides agreed to participate in the study following the meeting and two contacted me later. Another health care aide from the second Special Care Unit heard about the study and contacted me to volunteer to participate. The CNO of Facility A gave permission for me to interview participants during working hours at the end of their day shift.

Facility B did not have a research access process. I met with the Director of Care, again using the document, *Information about the Study*. The Director of Care gave me permission to conduct research on the site based on the research ethics approval I had received from the University of Manitoba and the approval for research access my study had been granted by the Winnipeg Regional Health Authority. She arranged that I meet with health care aides near the end of a day shift. At this meeting I brought the same materials and offered the same information as I did for the health care aides in Facility A. The health care aides in Facility B were pleased that research was being done about them and five health care aides agreed to participate in the study at the end of the meeting. Later one health care aide cancelled her appointment due to illness. Although offered another meeting time, this health care aide deferred.

The Director of Care arranged a meeting space for two interview sessions with individual health care aides. She also agreed that I could conduct the interviews at the end of the day shift.

My initial contact at Facility C was with the Chief Nursing Officer who referred me to the Chair of the Research Review Committee. I was required to complete a research access application. When research access was granted, I was directed to meet with two managers of the long-term care units. I met with them, using the *Script for Meeting with Managers* and the

document, *Information about the Study*. These managers supported the study and agreed that I could meet with health care aides during the end of the day shift. They arranged two meeting times during which I could interview health care aides and made a quiet room available for the interviews.

I contacted the Chief Nursing Officer of Facility D and was requested to contact the Manager of the Research Program. I was required to complete the facility's research access application. When research access was granted, I was asked to contact a Clinical Nurse Specialist, who arranged that I meet with the nursing managers at one of their regularly scheduled meetings. I used the same documents I used when meeting with other managers. One of the managers agreed to sponsor the study in the facility. She took copies of the consent forms and information about the study to distribute to the health care aides who worked on the Special Care Unit (SCU). Since the SCU was being renovated, the staff from this unit had been assigned to other units. These staff members were given permission to meet with me during their shift in a quiet space arranged by the unit manager. All of the health care aides interviewed to this point had worked on the day shift. At this site, I was able to interview five health care aides on the evening shift. The following day, I interviewed five health care aides working on the day shift. Although I could have continued interviewing at this site, nearly half of the sample was now made up of staff from the same facility and I was concerned about the introduction of bias into data analysis. After consultation with my co-advisers, I ended this stage of data collection.

Data Collection

There were two stages of data collection. In Stage One, health care aides participated in an individual audio-taped interview and in Stage Two, the same health care aides were invited to participate in a group interview.

Individual interviews. The individual interviews of 24 health care aides began in September 2014 and were concluded in mid-December 2014. These interviews involved two sets of questions, those included in the Demographic Form (Appendix J) and those contained in the interview guide, *Interview Questions for Individual Interviews with Health Care Aides* (Appendix H). The demographic form included question about the health care aide's: a) age and gender; b) ethnic origin and first language spoken; c) education prior to becoming a health care aide; and d) training to become a health care aides. The interview guide was designed to capture: 1) information about the health care aides, such as their reasons for becoming a health care aide and what they liked or disliked about being a health care aide; 2) information about the health care aides' perceptions of residents with dementia; and 3) descriptions of the health care aides' interactions with these residents during types of care provision. The development of the guide reflected the literature about health care aides in the United States and Canada as well as the literature about communication and persons with dementia. The development of the questions was also sensitized by my clinical experience as an occupational therapist working in long-term care facilities. The latter led to questions about interactions between health care aides and residents with dementia during morning and evening care, at mealtime, and during the provision of intimate care.

The questions in the interview guide served as initial questions that frequently led to more targeted questioning in response to other issues brought into the interview by the health care aides. This diversion from the initial interview questions led to a wider range of information about the health care aides' experience with the care recipients (Strauss & Corbin, 1998; Taylor & Bogdan, 1998). The strength of this method of questioning was that it recognized the health care aide as the expert, it led to a relaxed conversation between me and the health care aide and it

stimulated topics that were not included in the original interview guide. The result was a rich fund of data reflecting many aspects of each health care aide's experience with the residents.

Each interview began with me welcoming the health care aide and then reviewing the *Consent Form for Participation in an Individual Interview* with him/her. If the health care aide had not brought a signed consent form to the interview and continued to consent to participate in the interview, the health care aide signed the consent form at that time. I then signed that copy of the consent form, which I retained for my records. Both the health care aide and I signed a second consent form for the health care aide's records. In the process of signing the consent form, the health care aide was asked if he/she agreed to be contacted to participate in the group interview. If the health care aide agreed, he/she was asked to provide a telephone number or email address where he/she could be contacted in the section of the consent form recording his/her agreement to be contacted in the future. Finally, the health care aide was asked if he/she wanted to receive a copy of the study findings, in which case the health care aide was asked to provide a mailing address. I then asked the participant if they would complete the *Demographic Form*. The participant was informed that completion of the demographic form was voluntary and he/she could refuse to provide this information. All health care aides agreed to complete the form. Each *Demographic Form* was identified by a code number instead of the health care aide's name. All the health care aides agreed to the interview being audiotaped.

The individual interview was then conducted using the interview guide. After turning on two digital recording devices, I began the interview by thanking the health care aide for agreeing to be interviewed. I attempted to create a relaxed atmosphere by conducting the interview in a conversational style intended to encourage the health care aide to speak freely and openly (Taylor & Bogdan, 1998). Since many of the health care aides spoke English as a second

language, I used familiar and commonly used English words and phrases that would be familiar to the health care aides. I used attending behaviors to support the health care aide's response to the questions. These behaviors included leaning somewhat towards the health care aide, monitoring my voice tone, speaking clearly but not loudly, and looking towards the health care aide. Tentative listening techniques such as repetition, summarizing, and paraphrasing were used to ensure that I had captured the correct meaning of what the health care aide said (Martin, 2000). I usually shared with the health care aide that I was an occupational therapist who had worked on long-term care units and that I had frequently assisted health care aides with caregiving activities such as morning care and assisting residents at mealtime. This sharing of personal experience also helped create a comfortable atmosphere for the interactions between the health care aide and myself (Taylor & Bogdan, 1998). I ended the interview by again thanking the health care aide. The mean length of the interviews was thirty-five minutes with a range of fifteen to fifty minutes. Each health care aide received a small honorarium at the end of the interview.

Focus group interviews. Focus groups are a qualitative research method that involves semi-structured group sessions that are conducted in an informal setting and are facilitated by a leader. The strength of focus groups is that they allow the participants to share and compare their thoughts, experiences, beliefs and feelings (Morgan & Krueger, 1993). The informal interactions of focus groups can result in additional information to that requested in the interview guide. (Albrecht, Johnson, & Walther, 1993).

There were two steps in the recruitment of health care aides for the group interviews. When the health care aides signed the *Consent Form for Participation in an Individual Interview*, they each agreed that I could contact them to request their participation in the group

interview. Following the initial coding of data from the 24 interviews, I contacted each of them by telephone or email asking if they would participate in the group interview. These contacts were made four months after the last individual interview had been conducted. Nine of the participants in the individual interviews agreed to participate in a group interview. Three of these were from Facility A, two from Facility C and four from Facility D. None of the participants from Facility B agreed to participate. When contacted, one health care aide from Facility B told me she had expected to be contacted two months earlier and now would not be available due to holidays. Other participants from this facility either did not respond to my calls or said they were waiting for the first health care aide to return from vacation. I stopped attempting to contact them after another effort was made.

The focus group interviews were conducted during May and June of 2015. These interviews had to be scheduled outside of working hours because the participation of a number of the health care aides from the same unit at the same time would have been too disruptive to the unit's routine. I arranged to meet with the participants from Facility A in a conference room at their work site after the day shift was over. In Facility C the participants also agreed to meet after the day shift. The facility provided the same space used for the individual interviews. Two group interviews were arranged for the participants from Facility D. Both group interviews were conducted in a private room in a restaurant near the facility. Only one participant attended the first interview and three attended the second. Refreshments or meals were provided at all sessions. Again a small honorarium was given to each participant. A Research Assistant (RA) had been hired to assist with preparations for the interviews and to take notes during the interviews. The RA had previously signed the *Confidentiality Pledge for the Research Assistant* (Appendix M).

The purposes of the focus groups were: a) to achieve the health care aides' input about the results of the initial analysis of the data from the individual interviews; b) to introduce four questions that arose from this analysis; and c) to stimulate an exchange of ideas between the health care aides that would result in new information for future data analysis.

Each group interview began with thanking the participants and then reviewing the *Consent Form for Participation in a Group Interview* with the participants. The voluntary nature of their participation was emphasized as well as a review of the possible risks and benefits related to their participation. All the health care aides who attended the group interviews signed the consent form and were given a second signed form for their records. I again signed both copies of the consent form for each of the participants.

I facilitated each interview, using the *Focus Group Interview Guide* (Appendix I). The group interviews were audiotaped. As well, the (RA) also took notes during each interview.

The pattern of questioning used for these group interviews represented the *Funnel Design for Interview Guides* (Morgan, 2010) where more general questions are followed by structured, in-depth questions. The general questions came from the outcome of the initial analysis of the data from the individual interviews and gave the health care aides an opportunity to comment on these. The four questions that arose from this data analysis were integrated into the *Focus Group Interview Guide*. These questions were:

- 1) What were the influences that precluded the health care aide's caring attitudes?
- 2) What were the influences that precluded their insightful interpretations of the residents that were revealed in the data analysis?
- 3) What was the nature of the interactions of the health care aides with other staff members? The health care aides in the individual interviews rarely mentioned other team members including

nurses. How did this possible lack of interaction with other team members affect the health care aides' interpretations of the residents and their interactions with the residents?

4) What influence did formal health care aide training have upon the attitudes and perceptions of the health care aides?

Each group interview ended with a wrap-up of the information that had been discussed in order to provide a sense of closure to the interview session (Morgan, 2010). Each focus group lasted about an hour, with a range of fifty to seventy minutes. Having four group interviews allowed a comparison of each group's responses to the questions in the interview guide as well as a comparison of any new information brought by the participants to each interview (Krueger & Casey, 2009).

All the individual and group interviews were audiotaped with two digital recorders. The recording that had the best sound quality was retained and downloaded into a password-protected computer. A professional transcriber was hired to transcribe the data. The transcriber signed the *Transcriber's Pledge of Confidentiality* (Appendix L) prior to receiving any of the data.

The data gathered from the focus groups added to that gathered from the individual interviews in the following ways. First, the four questions in the interview guide led to in-depth discussions about the relationship of the health care aides with nurses. Concerns were expressed about the occasional lack of support from nurses when the health care aides requested assistance or attempted to pass their observations on to other team members or the physician. The questions in the interview guide also stimulated a discussion about the origins of the caring attitudes of the health care aides. During this discussion the health care aides spoke passionately about the qualities they needed to do their job, such as being caring and patient with the residents and having the courage to return to care for residents who had harmed them. However, the health

care aides could not identify the source of these attitudes. The focus groups also led to the health care aides stating their dissatisfaction with the staff education programs provided by their facilities regarding dementia care. Finally, one of the sessions involved a single male participant. During this session, this health care aide spoke about his experience as a male caregiver with both male and female residents. Since most of the participants were female, this interview added a new dimension to the concept of caregiving. This health care aide also expanded on the information already gathered about working with the constant threat of physical abuse from residents but from a male perspective. For example, he indicated that male caregivers may experience more aggressive forms of violence from male residents.

In the selective coding process, the findings from the focus group interviews reinforced how the personal characteristics of the health care aides facilitated the perception of the resident as a respected person. In the development of the contextual conditions of the theory, the relationship with nurses was used to add dimension to the concept of being a team member. The findings regarding staff education programs were identified as inhibitors of the perception of the resident as a care recipient.

Theoretical Sampling

The theoretical sampling methods described here are those of Strauss and Corbin (1998) since it is their mode of grounded theory that is used in this study. Strauss and Corbin state that theoretical sampling refers to data gathering methods used to explore how concepts vary in terms of dimensional range and properties. Different types of theoretical sampling are used throughout the processes of open, axial, and selective coding and the validation of theory.

In the initial stage of this study, theoretical sampling was used to select sites in which to conduct individual interviews. These sites varied in characteristics such as size and available

range of services, whether they were faith-based facilities or secular facilities and whether they were managed by a board of directors as opposed to the Winnipeg Regional Health Authority. In open and axial coding, the data gathered from the interviews conducted with health care aides employed at these facilities were conceptualized and the concepts put into categories in relationship to each other. It was assumed that the different characteristics of the four facilities would lead to a variation in the data and therefore to a wider range of properties and dimensions of the resulting concepts and categories.

Theoretical sampling was also used in the individual interviews with the health care aides. As stated previously, I developed an interview guide for conducting these interviews. The questions for this guide were developed from the literature and from my personal experience as an occupational therapist working with residents with dementia in long-term care facilities. Although the same guide was used in each interview, I did not follow it rigidly. As I entered into a conversation with each health care aide, the open-ended questions of the guide frequently resulted in the health care aide taking his/her own path in addressing the question I had asked. When this occurred, I temporarily abandoned the guide and used probing questions about the event or happening that the health care aide was describing. I did this to encourage the health care aide to pursue his/her train of thought. These probing questions represented theoretical sampling since they were developed spontaneously to lead to information I had not heard before or expanded on information I had already encountered in other interviews. This information would add to the dimensions and properties of the concepts that were derived during analysis of the data. Throughout the interview, I would return to what seemed relevant portions of the guide but again prompted the health care aide to provide the individually located information that he/she wanted to bring to the interview.

The third example of theoretical sampling used in this study was use of the data already collected from the individual interviews. In my first attempt at open and axial coding, the data was conceptualized and analyzed using comparative analysis with concepts being identified and then clustered into categories and subcategories. Unfortunately, the results of this coding did not address the research question of how health care aides perceived and understood the residents. Instead, the categories and subcategories that emerged revealed the perceptions of the health care aides about their role instead of their experience of interacting with the residents. When I went back to these categories and to the data supporting them, I realized that the concept that continued to emerge was the health care aide's perception of the resident as a person. At this point I was reminded of the work I had done in a previous study where I had used a literature review to develop ten concepts of personhood and persons with dementia. These concepts then served to provide theoretical sensitivity for a renewed effort to use open and axial coding with the same data. I returned to the data already collected and located events and happenings in the data that provided dimension and properties for the various concepts about the resident being perceived as a person. Events and happenings included the health care aide encountering conflict with other staff, developing a relationship with the resident, providing morning care as opposed to evening care, feeding residents. They also included the many instances of health care aides communicating with residents. Using this sampling method and the theoretical sensitivity provided by the ten concepts of personhood, the categories and subcategories were developed that eventually evolved to the final theory. I again returned to the data to further establish the relationships of the concepts and their properties and dimensions during the process of selective coding and validation of the theory.

The development and implementation of this study presented constraints to theoretical sampling. In the development of the study, I was required to meet the requirements of my committee and the Research Ethics Board. For example, I could not move spontaneously from one site to another if I wanted to explore events or happenings that would add to the conditions, dimensions or properties of a particular concept or category. Instead, I followed a carefully prescribed process for gaining access to each facility and then recruiting health care aides in that facility. As well, although being permitted to conduct interviews during the health care aides' working hours facilitated the recruitment of health care aides, I was restricted to interviewing only those aides who not only voluntarily consented to participate in the interviews but who were available when I was allowed an interview space on site. I could not return to ask them further questions or recruit other health care aides. However, Strauss and Corbin address this issue by saying that the researcher often has to take who or what he or she can get in terms of a sample (Strauss & Corbin, 1998, p. 208). Despite these constraints, the theoretical sampling techniques used in data gathering facilitated the formation of fully developed categories and statements of relationship of the data.

Field notes. The field notes consisted of notes I took during the individual interviews and the notes the RA took during the group interviews. I developed a form for taking notes made up the major headings of the interview guide. The field notes from the individual interviews were each given the same code number as the number on the participant's demographic form. The field notes from each interview included the date of the interview and information about the interview site. They also included my observations about how the participant responded to the interview process and any comments or observations the health care aide made to me outside of the actual interview that added context to the interview. During each individual interview, I

attempted to capture the main ideas expressed by the health care aide under each heading of the interview guide. Due to the intensity of the interview interaction and the digression from the sequence of interview questions, I frequently did not complete these notes until later when I listened to the audiotape. The number of minutes of each interview was later added to the field note for each interview. The field notes for each interview had the same code number as the *Demographic Form*. The RA took notes during the focus groups. I made a similar form for this notetaking, again using the headings from the *Focus Group Interview Guide*. The RA and I reviewed his/her notes immediately after each group interview. I took these notes with me to compare the notes with the recorded interviews and to use them for data analysis. The notes from each focus group were identified with the code number assigned to each of the four group interviews beginning with Focus Group 1.

Memos. The memos reflected the effect of the researcher's background, perceptions, and professional experience on the research process (Hall & Callery, 2001; Krefting, 1990). Memos related to this study served as a written record of the decision making process throughout recruitment, data collection, and data analysis processes (Glaser, 1978). One memo consisted of a record of the main themes of each of the 24 individual interviews. These memos served especially as a record of the reflexive process used during data analysis, including questions that arose during these processes.

Data Analysis

The data analysis for the demographic data involved developing frequency values for the various categories of data. When reporting demographic data, an effort was made to protect the confidentiality of health care aide. For example, data about countries of birth were merged into

general categories, such as “European”, rather than revealing the names of the actual European countries represented.

The analysis of data from the individual interviews began with listening to the audiotaped recording of each interview one or more times. To begin the process of developing concepts from the data, I compared the recording of each interview with the typed transcription from that interview. After completing a process of line by line or paragraph by paragraph comparison for four interviews “discrete incidents, ideas, events, and acts” were identified (Strauss & Corbin, 1998, p. 105). Code words were entered in the margin of the hard copy of the transcript. Using constant comparative analysis (DePoy & Gitlin, 1998), these codes or concepts were compared to determine their mutual exclusivity.

During axial coding, categories and subcategories of data were revealed. The relationship of these categories and subcategories remained fluid, with some categories merging into others. Memos recorded the development of these categories, the questions that emerged, and the resolution of these questions. A running memo of the synopsis of each interview was created that linked the health care aide, identified by their code number, with their demographic data and the field notes from the interview to compare the themes that were evident from each interview. This process prompted questions about the relationships of concepts in the developing categories and subcategories.

Following the identification of the major categories and the development of their relationship with each other and with subcategories into a theoretical scheme, analysis proceeded to selective coding. Selective coding is the process of integrating and refining categories to a higher level of abstraction and overarching theoretical scheme (Strauss & Corbin, 1998). I turned to memos, diagrams, and storylines to further explore the relationship of the categories until a

central category became evident. This central category or core variable was related to all other categories, addressed the variation in patterns of behaviors, and helped to integrate the other categories (Speziale & Carpenter, 2007; Strauss & Corbin, 1998).

Refining of the theory involved validating the theoretical scheme by determining how well it fit with the data. I returned to portions of the data but also to the synopsis of each interview that captured the main themes each health care aide brought to the analysis. Throughout the writing of the findings, I continued this process of validation, looking for gaps in the categories or any occurrences where the findings did not reflect the data. A re-reading of the field notes further validated the theory.

Ethical Considerations

Ethics approval for this study was originally obtained from the Education/Nursing Research Ethics Board (ENRB) of the University of Manitoba in in May, 2010. Following my being granted leave from the study in 2012, it was renewed in May, 2014. The Winnipeg Regional Health Authority (WRHA) granted research access for the study within the Winnipeg Health Region in June, 2010. This research access was re-confirmed in May, 2014

The specific ethical concerns related to this study stemmed from health care aides being considered a potentially vulnerable population. These concerns were: a) respect for human dignity; b) respect for free and informed consent; c) respect for vulnerable persons; and d) respect for privacy and confidentiality (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences & Humanities Research Council of Canada, 2014).

In this study, the possible risk to a health care aide during an individual interview was his/her experiencing feelings of distress as a consequence of discussing his/her experience with

residents with dementia. In the event that a health care aide indicated these feelings, either through words, or behaviors, such as weeping, I was prepared to stop the interview and turn the recording device off. This occurred during one interview when a health care aide became tearful when discussing his/her feelings about residents. I offered to end the interview but the health care aide said he/she wanted to continue.

Anonymity and Confidentiality. All information about the participants was kept confidential through the use of the following measures: a) the participant's name and assigned code number only appeared together on a Master List that was kept in a locked filing cabinet separate from the consent forms and raw data; b) all email contact with participants was conducted on the password-protected computer; c) the demographic forms, field notes, and transcriptions from each interview were stored in the locked filing cabinet; d) all memos and data analysis were developed electronically and were stored on the password-protected computer; and e) all participants in the focus groups, the RA, and the transcriber signed pledges of confidentiality.

Two digital recorders were used to record the interviews. The recording that had the best sound quality was downloaded into the password-protected computer. This recording was then loaded onto a portable memory device which was hand delivered to the transcriber. The transcriber sent the transcribed data from each interview to me electronically. The transcription for each interview, with the participant's code number, was retained in the password-protected computer. The transcriber delivered the memory device directly to me. After comparing the transcribed data to the audiotaped recording and finding that it was an accurate copy of what was recorded, I deleted the recordings from each recorder.

In addition, there will be no secondary use of the data. All recordings, transcriptions, forms and field notes will be destroyed when I and my advisory committee are satisfied that the study has been completed or within two years of completion of the study. The transcriber has been asked to remove the audiotaped recordings and transcriptions from his/her computer. I have been the only person with access to the data, except for some data being shared with members of my committee. In any publications or presentations arising from the study, all identifying information about the participants will be removed.

Reciprocity. During the recruitment process, I agreed to make a presentation to the managers of each of the facilities in which the study was conducted. As well, I have agreed to provide each of the study participants with a report about the study findings. In developing these presentations and reports, I will use the following peer-reviewed processes for knowledge translation.

Knowledge Translation.

The Canadian Institutes of Health Research (CIHR) define knowledge translation (KT) as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system”. This process takes place within a complex system of researchers and knowledge users (CIHR, 2016). One approach to knowledge translation is called “end of grant KT”. In this approach the researcher develops a plan for making the knowledge resulting from the research available to users (CIHR, 2016). Graham and his colleagues wrote that researchers can tailor or customize both the message and means of its transmission for specific audiences (Graham et al., 2006). Knowledge dissemination and knowledge diffusion are two methods I can use to achieve this goal. Knowledge

dissemination involves planning and executing interventions to promote and facilitate the use of knowledge and includes adapting the message to meet the needs of a specific audience.

Knowledge diffusion refers to passive activities such as publishing articles or making knowledge available on the Web (Graham et al., 2006). In each of these efforts of the dissemination and diffusion of the information from this study, I will refer to the *Knowledge-to-action Process* (Graham et al., 2006). This model shows that to achieve the transition of knowledge to practice, one must adapt the message to the local context while assessing barriers to knowledge use. Using this model, I will attempt to increase awareness of the findings and recommendations of this study with change agents. Change agents are individuals and organizations who have the influence to either increase or decrease the possibility of the utilization and implementation of the recommendations coming from the study (Estabrooks, Thompson, Lovely & Hofmeyer, 2006; Graham et al., 2006). Dissemination of this information will be achieved through meetings with stakeholders, such as representatives of the Winnipeg Regional Health Authority, senior management of long-term care facilities and directors of organizations such as the Manitoba Alzheimer Society and the Long Term and Continuing Care Association of Manitoba. I will also submit abstracts for conference presentations to organizations such as the Long Term and Continuing Care Association of Manitoba, the provincial and national Alzheimer's societies and the Canadian Palliative Care Association. The diffusion of the findings of this study will be accomplished through publications in journals of health care management, geriatric and dementia care and journals related to clinical practice. As well, I will attempt to meet with senior representatives of the Health Care Aide Program at Red River College as well as senior representatives of Robertson College and Herzing College. The purpose of these meetings would

be to stimulate discussions about incorporating information about person-centered care and communication and dementia into their curriculums.

Rigor

Throughout data analysis and the development of theory, various strategies were implemented to establish the fit, plausibility, credibility, transferability, and confirmability of the study findings.

The following strategies were employed to establish the credibility of this study:

1. There was prolonged and varied field experience. I interviewed 24 health care aides from four long-term care facilities. Further contact with the health care aides occurred during the focus groups. Observations about the health care aide and the environments and occurrences associated with each interview were recorded in field notes, which were reviewed during the processes of data analysis and theory building and theory validation (Burns, 1989; Strauss & Corbin, 1997).
2. The focus groups provided an opportunity for input from the health care aides who participated in individual interviews about the results of the open and axial coding of the data from these interviews.
3. A statement of my assumptions and beliefs was developed with my advisory committee prior to beginning data collection and analysis to acknowledge my prior professional experience as an occupational therapist. This document helped to reveal personal biases that might influence data gathering and analysis (Cutcliffe, 2000). The reflexive processes of field notes and writing memos required further questioning of the effects my beliefs and values on the various stages of the research process (Hall & Callery, 2001).

4. In the early stages of data analysis, some of the transcripts were shared with committee members who participated in the early stages of open and axial coding.

Efforts to achieve transferability of the findings of this study included the careful description of the health care aides of this study from field notes and the collection and analysis of demographic data. To achieve dependability or reproducibility in this study, an audit trail was maintained of the stages of the coding processes and then of theory development. This audit trail included records of the developing codes, memos and diagrams and the use of theoretical sensitivity (Glaser, 1998; Strauss & Corbin, 1998). One component of the audit trail was a synopsis of each interview, which captured the main themes of the interview. This synopsis, along with field notes, was also used to determine the “fit” or plausibility of the final theoretical construct.

The strategies that were employed to achieve confirmability included awareness of my personal assumptions, beliefs and biases and the development of the audit trail.

Summary

The methods and procedures for conducting the study have been presented in this chapter. These include the rationale for using grounded theory methodology and analysis, the processes used for recruitment of the health care aides as well as the processes employed for data collection and analysis. Ethical considerations specific to this study and measures used to establish academic rigor of the study have also been presented as well as processes for knowledge translation.

Chapter Five: Overview of the Theory

This chapter will be used to present an overview of the theory, “The Resident being perceived as a Respected Person”. This overview will be used to describe how health care aides perceived and understood residents with dementia and how these perceptions and understandings influenced the health care aides’ interactions with these residents. The overview will be preceded by a description of the study sample and followed by a discussion of the contextual conditions in which the health care aides perceived and interacted with residents with dementia.

The four chapters following this chapter one will adhere to the same format: a) a presentation of the concepts of personhood associated with the perception of the resident; b) the themes related to the perception of the resident; c) the facilitators of the perception; d) the inhibitors of the perception; and e) the consequences of the perception. A summary table is provided at the end of each of these chapters to present an abbreviated representation of the facilitators, inhibitors, and consequences of the interpretation of the resident presented in the chapter.

The Study Sample

Twenty-four health care aides consented to participate in this study. They were employed in one of four different long-term care facilities in Winnipeg. All worked with residents with dementia who lived on specially designated care units. A description of long-term care facilities in Winnipeg is presented in Chapter Two. Table 4 is used to show the distribution of health care aides who took part in interviews.

Table 4.
Distribution of Participants from Four Facilities

Facility	Individual Interviews	Focus Group
Facility A	5	3
Facility B	4	0
Facility C	5	2
Facility D	10	4
Total	24	9

Twenty-one of the health care aides were female (Table 5). The distribution of their ages and gender, as well as the proportion of those who were born outside of Canada and having English as a second language, corresponds to the description of this category of health care workers in long-term care facilities across Canada and in the United States.

Table 5.
Participants' Demographic Information

Demographic Characteristic	N=24	%
Female	21	87.5
Male	3	12.5
Age 25-44 years	9	37
Age 45-55 years	10	42
Age 55+	5	21
Born outside Canada	15	62
English as a second language	15	62

Some of the Canadian-born health care aides had attended university prior to becoming health care aides (Table 6). Of the foreign-born health care aides, a number had received either a college education or vocational training outside of Canada. A number of the health care aides born outside of Canada had previous careers in their home country in a variety of professions, including teaching, midwifery and business management. However, their credentials were not recognized in Canada and therefore they decided to become health care aides.

Table 6.
Participants' Education Prior to Becoming a Health Care Aide

	N=24	%
College education in Canada	3	12.5
College education outside Canada	4	17
Vocational training in Canada	4	17
Vocational training outside Canada	1	4
Partial nursing programs	3	12.5
No prior education	9	33

The health care aides who were participants in the study represented a variety of health care aide training programs (Table 7). Five of the older health care aides had been trained through programs developed by individual facilities or religious organizations to address a shortage of health care aides that existed at that time. Eighteen (75%) of the health care aides had graduated from technical colleges certified by the Association of Canadian Community Colleges. However, the training requirements had changed over the years, with programs being expanded from a few weeks to the current requirement of twenty-two weeks.

Table 7.
Participants' Training to Become Health Care Aides

	N=24	%
Technical College/Collegiate	18	75
Courses provided by Employer	5	21
No Formal Training	1	4

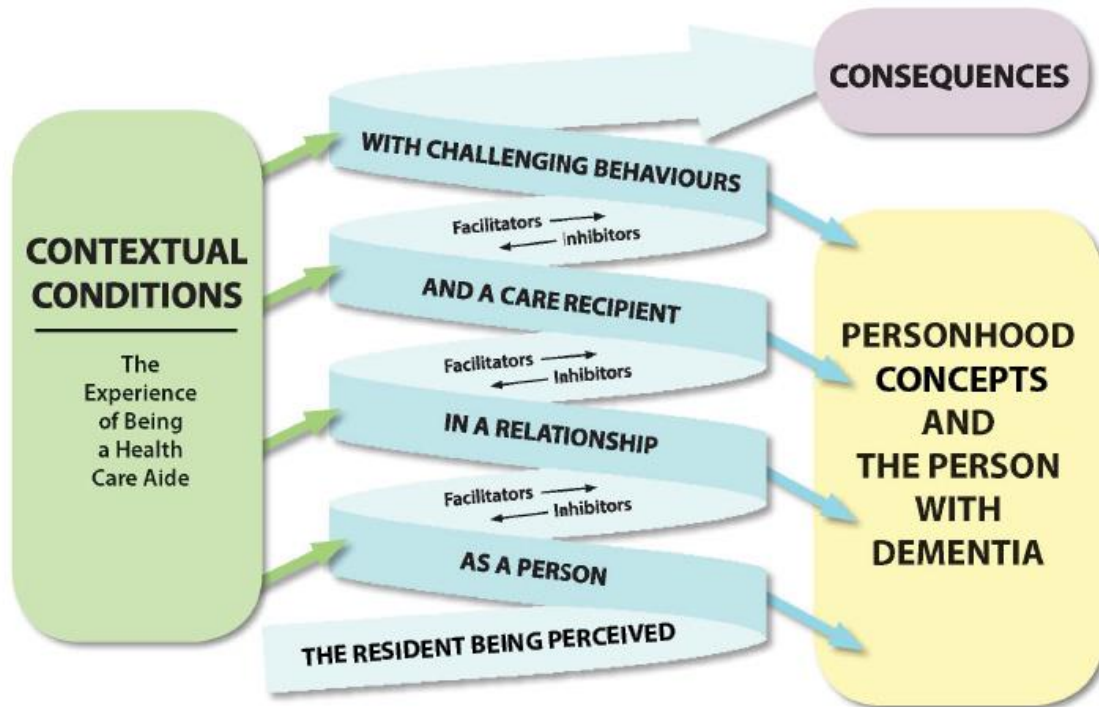
The reasons the participants chose to become health care aides varied. A few had lost previous positions. For some this had occurred in the same facility where they were employed at the time of the interview. A number of those who lost their jobs had hoped to re-enter the work force quickly and saw becoming a certified health care aide after twenty-two weeks of training as

a way to do this. Others were attracted by the possibility of job security and a benefit plan. A few of the health care aides had wanted to become nurses but for various reasons chose to become health care aides instead. Others who considered becoming nurses believed that working as a health care aide would give them basic nursing skills and help confirm their choice of nursing as a future career. Finally, some were attracted to becoming health care aides because they wanted to work with people. Many of these had previous experience providing care to family members. Some simply liked elderly persons while others talked of being influenced by the culture of their home country to care for older persons.

Overview of the Theory: “The Resident being perceived as a Respected Person”

The central category of this theory is “The resident being perceived as a respected person” (Figure 1). All of the health care aides perceived the resident as a unique and respected person continuing to live out his/her life story despite the onset of the illness and the resident’s admission to a long term facility. This perception reflected three concepts of personhood. These were: a) personhood being a status conferred by others; b) the absolute person possessing the innate essence and uniquely human quality of being a person and c) personhood and the person being seen to live out their life narrative. The health care aides refused to define the resident in terms of the resident’s disease or to perceive the resident as being infantile. Instead, they understood the resident as a person continuing to live out his/her life story. Some health care aides referred to the possibility of themselves or their family members being in the resident’s place at some future time, thus seeing the resident as “Someone who could be me someday”.

Figure 1. The Resident being perceived as a Respected Person



The health care aides spoke of their interactions with the resident within the context of being in a relationship with the resident. This understanding reflected the personhood theme of transcendence, with the resident with dementia being seen to express his/her unique qualities and essence of a person through a relationship with the health care aide. It also reflected the concept of personhood and personality, with the resident being understood to derive meaning from this relationship. The resident was also perceived as a vulnerable person who required the health care aide's care and protection. This perception was a result of the resident experiencing significant losses due to dementia, living in an unfamiliar environment, and no longer being able to represent his/her needs. With these perceptions of the residents as well as the health care aide's

emotional responses to the residents, the health care aides made efforts to develop a relationship with each resident. This relationship facilitated the health care aides' providing care to the resident as well as their coping strategies during the resident's periods of disturbed behaviors. The health care aides spoke of a mutual relationship between the resident and the health care aide, with the resident responding spontaneously to the health care aide in both positive and negative ways. These spontaneous interactions included the resident expressing affection for the health care aide or being verbally abusive to the health care aide.

The health care aides also perceived the resident as a person who was a care recipient as a result of each resident's cognitive, physical, and mental losses due to the resident experiencing an irreversible disease. This perception reflected the personhood themes of: a) personhood and embodiment, with the resident existing in a physical body that needed to be moved, lifted and cared for by the health care aides; b) personhood and language, with the health care aides using communication enhancement strategies to continue to interact with the resident; and c) personhood and occupation, with the health care aides continuing to engage the resident in the meaningful occupations related to self-care. The health care aides attempted to adapt their care strategies to the unique physical and emotional needs of each resident. The combination of a health care aide's relationship with the resident and her/his insight into the resident's needs was especially useful during potentially challenging interactions with residents such as during the provision of intimate care, when diverting the resident from potential harm, or when attempting to calm the resident during periods of the resident's agitation.

All health care aides spoke of the residents being capable of agitated and even violent behaviors. Residents could be threatening, unpredictable, verbally or physically abusive and a risk for injury to other residents as well as the health care aides. However, the health care aides

perceived the residents as not being held accountable for these behaviors. Again the health care aides spoke of acting within the relationship they had developed with a resident when attempting to interact with an agitated or a violent resident. The interactions of the health care aides with residents with challenging behaviors reflected many of the previous concepts of personhood but especially the concepts of person and the regard of others. The health care aides continued to perceive the resident as a person despite the resident's challenging behaviors but also understood that the resident's previous history of abuse might have been a contributing factor to their aggressive behaviors. The latter perception of the person reflected the personhood concept of remembering one's personal history.

The facilitators of these perceptions of the resident by the health care aides were primarily the personal characteristics of the health care aides. These included the belief of all the health care aides that residents with dementia continued to be persons despite the effects of the disease. The health care aides also spoke of their ability to engage and develop relationships with the residents and their curiosity and initiative that led them to learn the residents' life stories. Other personal characteristics were the health care aides' commitment to providing good and compassionate care, their insight into the emotional needs of the resident as well as their ability to identify and respond to the unique care and communication needs of the resident. They also spoke of their understanding of the need to negotiate and collaborate with the residents. The health care aides each brought the wisdom gained through years of work experience with residents with dementia as well as the experience some had gained as informal caregivers with loved ones. The contextual facilitators of this perception of the resident were policy changes that permitted health care aides to read the medical record and life history review of each resident and

facility in-service programs. As well, some facilities implemented “Continuity of Care” policies that made it possible for the same health care aide to provide care to the same residents.

Inhibitors of this perception of the residents included the personal characteristics of a very few health care aides. These health care aides preferred to work with cognitively intact individuals or had difficulty relating to some residents, including those who were violent. The most important inhibitors of this perception of the resident were time constraints, staff shortages, and the attitudes and behaviors of other staff members who did not support the health care aide’s understanding of the resident or did not share the health care aide’s work ethic. Although these work stressors did not prevent the health care aides from perceiving the resident as a respected person with whom they were in a relationship, they frequently prevented the health care aides from having the time, resources, and supports to act on this perception

One of the significant consequences of the perception of the resident as a respected person in a relationship with the health care aide was the communication strategies adopted by the health care aides to develop and maintain relationships with residents, facilitate care, and manage the resident’s challenging behaviors. The health care aides described using a variety of speech accommodation and communication enhancement strategies. These included health care aides modifying their linguistic, vocal, and nonverbal aspects of communication. For example, health care aides spoke of using the resident’s preferred name to show respect, choosing words familiar to the resident, keeping their voices low and speaking slowly. They also used nonverbal communication strategies such as touch, gestures, facial expressions and mimicry in their interactions with the resident. Other consequences of this perception of the resident were the health care aides’ efforts to learn the resident’s life history, including developing relationships with family members. A consequence experienced by the resident was demonstrating

empowerment to interact spontaneously with the health care aides and to occasionally become active participants in their own care.

Contextual Conditions: The Experience of being a Health Care Aide

Although most of the 24 health care aides had graduated as trained health care aides from a certified technical college, they were all unregistered and unregulated health care workers.

However, some health care aides were able to articulate their accountability to supervisors, residents and family members. One health care aide stated:

...we are non-professional staff and nurses are professional staff. But all those things apply to us. We are accountable. People can [make complaints about a staff member to a manager or a family member can]. (Focus Interview 3:2260-66)

All facilities offered staff education programs to add to the information the health care aides gained in their formal training programs. These ranged from a mandatory education day once a year to brief sessions once or twice a year. Most of the health care aides stated they applied some of what they learned from these programs to the residents in their care, especially residents who presented some unanswered care need. As one health care aide said:

Oh for sure... Education is always good... because there's probably new things that are tried... Then it's, oh well, we'll try that. And then in the back of your mind [you think of] a certain resident that you've tried everything else... but it's trial and error. (Interview 1011:1128)

One standardized program offered to most of the health care aides was the P. I. E.C.E.S programs, which stands for Physical, Intellectual, Emotional Capabilities, Environment and Social and was designed to help caregivers find creative ways to manage behaviors related to dementia (P.I.E.C.E.S, 1997; Winnipeg Regional Health Authority, 2012). Other health care aides spoke of independently reading literature about dementia. However, most health care aides agreed the most important part of their learning was the result of their work experience, learning

from other health care aides and the process of “trial and error”. One of the health care aides described the staff education in her facility in the following excerpt:

Well we have, um, one a year. It’s called professional development day and it’s mandatory for all, nurses and aides... and it deals, not specifically with Alzheimer’s but that’s included. But in addition to that, all floors, every week, every month it seems are various little education packages which we’re required to do on our so-called down time. (Focus Interview3:220-22)

Despite their health care aide training and staff education programs, the health care aides demonstrated a limited knowledge about dementia. Most could describe the characteristics of a person with dementia but had little understanding of the underlying causes or physiological changes related to diseases leading to dementia. This is illustrated in the following interview excerpt:

It’s Alzheimer’s so it’s like a fine line between. I don’t know the definitions... the difference between the two but... for me dementia is like a person that is like very, on the forgetful side... It’s like, I always explain it as the motherboard like ... like kind of just fusing off and being more forgetful... Well it has to do with the brain. (Interview 1012:143-81)

One of the major facilitators of the health care aides’ perception of the resident as a respected person was the health care aides’ commitment to quality and compassionate care. One health care aide described this characteristic as he/she saw it in other health care aides. To this health care aide, it appeared that other health care aides went far beyond the expectations of their role.

When it comes, well when it comes right down to it, you know, we all have pieces of paper. But there are certain health care aides... there’s certain girls on the floor that just stand out there. They really are. Like they’re just, they’re just so kind and they’re, I think I do my job well. But these ones really stand out. They really stand out. They’re just top of the line. And they mean so well. You know, they’ll go out of their way to bring things from their own

house with their own money. That kind of stuff, right. And you can tell they're really good. And forget the piece of paper, you know. They are so, they are so much more valuable to [facility name] than anybody, than 10 pieces of paper. (Focus Interview 3:2355-67)

Other health care aides referred to the pleasure they experienced using their skills to enhance the quality of care of the resident. The following health care aide spoke of the collaboration with other team members that contributed to the care of the residents. He/she was pleased that, because he/she made a point of interacting with residents, he/she had become a role model to other health care aides on his/her team.

So now like I've got different coworkers, some bring one thing to the table that I never would have thought to do. So I tell them it's a good idea. And they know I chat a lot with residents. And they say, there goes [interviewee name] again. But they know I get the results... that I want or that they. I want them to feel good. So I notice a lot of them chat with the residents more. (Interview 110:1182-85)

Another contextual condition related to the perception of the resident as a respected person was that all the health care aides were members of a care team. Care teams on special care units are made up of nurses, physicians and an assortment of allied health staff members. However, during the individual interviews, the health care aides referred almost exclusively to their experiences, both positive and negative, working with other health care aides.

Many of the health care aides spoke of feeling supported by their fellow health care aides. These health care aides worked together, performing similar tasks with many of the same residents. They offered support to each other such as providing a listening ear when problems occurred with residents. This was the case, for example, when a health care aide was injured by a resident.

Health Care Aide: Or there's been a critical incident of aggression with the resident and it's like, and you're really upset. Someone hit

you... and you know we can all empathize and side with each other and, you know what I mean, and it's just to talk about like... talking to a counsellor but you're talking to your coworkers.

Researcher: [You've got a] counsellor right there.

Health Care Aide: Exactly. Yea. Because we all can relate. We all have experienced it. (Focus Interview 4:1314-45)

Health care aides observed that working with a congenial health care aide partner helped get the work done more quickly and without conflict. One health care aide stated that the physical and mental stress of providing care to the residents was eased when he/she worked with an agreeable partner.

The days goes fast. The days is easy with the residents. You're happier, you know. Your work is done, you know, like without much hassle. (1018:161-171)

Another health care aide described the experience of having a challenging day. He/she observed that having a good partner made the work seem easier and helped with negotiating with residents.

Because I notice too that I, there will be a heavy day where there's chaos, where there's fighting, the residents are fighting. And just chaos with the residents. But if you're working with someone good, it's easy to like... redirect them, the residents... It's easier like that... it's like if you're enjoying work you don't notice how heavy and how mentally straining it is. (Interview 1003:861-73)

However, one of the most negative contextual factors associated with the health care aides' perception of the resident as a respected person was conflict with other health care aides. Health care aides participating in the study observed that other health care aides could cause trouble for them or others during the health care aides' shifts. Many health care aides complained that other health care aides were not prepared to work as hard as they were, leaving these health care aides to complete the work and feeling stressed. The health care aides spoke of their distress when the behaviors of other staff members created problems for the residents. This was the case,

for example, when staff members did not speak English to English-speaking residents. What made these situations even more problematic for the health care aides was their inability to effect a change in the behavior of these other staff members, as illustrated in this excerpt:

Like if you get two people they go in there and I'll be honest, I'm very honest with you in what happens a lot is, we have a lot of people coming to this work because it's the job with security and pension plan. And what happens is, they just want to get it done quick. Let's just get it done. Sometimes they even go in there and they speak different languages and in front of the residents. Our residents already very confused, they don't need that. They don't need that. They don't need another, two people speaking a different language in front of them to even make them more irritated... And that frustrates me a lot. You can go up to the manager and tell her what's going on. But if the RNs and the manager don't take those people aside and say, listen, this is the way it is. This is the way it has to be. [And]it doesn't. It doesn't. And that happens everywhere. (Interview 1027:129-57)

Another source of stress for the health care aides was working with temporary staff members who were unfamiliar with the residents and the routine on the unit. This health care aide described feeling responsible for providing direction to a temporary staff member who then resented the health care aide's suggestions.

Health Care Aide 1: I know. Understanding what to do because they don't know the routine... And, and they think that I am the boss. And I said, oh next time, and I talk to them nicely. But still.

Researcher: When you say you are the boss, it means that they don't like you being the boss?

Health Care Aide 1: That's right...They don't like... to be told.

Health Care Aide 2; Maybe they have more experience and more seniority and they don't like to be told.

Health Care Aide 1: And I said to them... I said to them, oh you know what, I'm just giving you, I'm directing you doing the care ... because you don't know the routine.

Researcher: So you're taking responsibility?

Health Care Aide 1: Yes. If your partner is a float, you're, you're the one who's taking the responsibility.

Researcher: So to provide care to this resident, you take responsibility and the result is that somebody isn't happy with you.

Health Care Aide 1: Yes, that's right. (Focus Interview 2:270-382)

The relationship between the health care aides and nurses was seldom mentioned in the individual interviews. When asked during the focus groups if the health care aides received the support they needed from nurses, one response was that this support was unnecessary and that the health care aides worked independently of nurses. Everyone on the unit knew the residents and did their work without directions from the nursing staff. However, nurses occasionally provided assistance to a health care aide. One health care aide stated:

To answer that question, there isn't much support that we really need because, you see... because I'm not [sure] what you mean by support. We don't need support because we all know the residents... Or another example. Sometimes, you know, for the most part nurses just do pills and charting. But if one resident didn't like the two or three aides working on the floor and happen to have an affinity for the nurse, well then it's common sense, you know, would you mind giving them care because she'll do it? And so it's a reciprocal, you know. We help them and they help us. (Focus Interview 3:895-924)

Another health care aide referred to his/her relationship with nurses. Instead of expecting direction or support from the nurse on duty during a shift, this health care aide strategized how to manage his/her day according to the amount of support he/she had learned to expect from that nurse.

My relationship with my nurses are, I have a great relationship with my nurses. I have a great relationship with my manager. But I think it's just the person that I am. It's how I deal with that. And how I cope with the people that I have to work with. If I know that the nurse that I'm working with that day is not the person that would help me out or when you call the bell, or, you know, answer

the bell and what not. I expect that. I just have to arrange my day accordingly. (Interview 1019:334-42)

The health care aides spoke of a breakdown in communication between the health care aides, nurses, and other team members. A health care aide cited an example of when the health care aides' observations about changes in a resident's behavior, such as the resident becoming more aggressive, were not passed on by nurses to health care aides on other shifts. As well as not addressing the resident's needs, this inaction put other staff members at risk since they are not warned that the resident had become violent. In another instance, the observations of health care aides about a resident were not considered when a temporary or "casual" nurse recommended medication changes for a resident. The health care aides were concerned that ignoring the input from direct-care staff might have negative consequences for both the resident and the health care aides providing direct care. The health care aides in the focus groups complained that their observations were often not entered in the "report" book and usually not put in the medical record, which is the document read by the physician. One health care aide said she would then wait for an opportunity to pass the same information on to another nurse in the hope that the information would be communicated to other staff or the physician. These events left the health care aide feeling unable to adequately represent the resident's needs.

Researcher: So there is a certain element of powerlessness.

Health care aide: Absolutely. We were just talking about it today. Sometimes you'll have a resident... like [we had] today [who] was getting aggressive and they don't, they don't write it down or, and someone said, oh, the casual will say, we're going to change so and so's meds. Things seem to be good. Another girl told me this. And she said, what do you mean he's getting good, she says, he's not good at all. We can't even get him to get changed in the morning. So whatever we're reporting that he's not changing today. He won't let us do his care. They may not, they may put

[the observations] in [the report book] but maybe they don't put it in the chart.

Researcher: And don't tell the doctor.

Health Care Aide: Then the doctor doesn't see because he can't read it. It's not, it is in the report book but not in the chart. We're not sure, I don't know how that works. And then they're thinking, let's decrease his meds because he's been good now. And then they want to change... (Focus Interview 4:961-1003)

Health care aides frequently interpreted the contextual factors of their understanding and relationship with residents in terms of the resident's experience. One of these factors was the special care units on which the health care aides worked. These units were designed to meet the needs of persons with cognitive impairment. Some health care aides preferred working on these units because residents were free to go where they wanted and were separated from mentally competent residents who might criticize them. As well, health care aides observed there was usually more staff working on these units who were experienced working with residents with dementia.

And I really enjoyed that because... I liked the locked units. I liked the units because [the residents are] more free to go and everybody's, you know, you don't have residents that are with it that are going to criticize them as much. Everybody's kind of in the same boat. And I always find the staff on those units a little better. (Interview 1011:46-52)

However, other health care aides commented that the locked units were too institutional looking and were not always designed to meet the perceptual needs of the resident. As well, many residents became agitated trying to find a way to leave these units, which resulted in the health care aides having to redirect and attempt to calm the resident. The following health care aide described the situation of a resident attempting to leave the unit to return to his/her home.

Because they do feel trapped. Like you can't leave... it's nighttime, they should be home with their wives or their husbands... And

that's generally what they're doing. They're asking about their wives or they're upset because they feel like this is not home. (Interview 1-16:775-98)

A major concern of health care aides was the insufficient number of health care aides on each shift. The consequences of this, as seen by the health care aides, included a risk to resident safety, reduction and inconsistency in the quality of care, and increased workload for these health care aides when other staff members did not report for work. Some health care aides spoke of having to address the needs of a number of residents at one time. The result was a conflict between meeting the resident's basic care needs while attempting to respond to the resident's social and emotional needs. This is illustrated in the following exchange during a focus group:

Researcher: So when you're short staffed, which of the residents needs are not met as much as others do you think?

Health Care Aide 2: Maybe their social needs. Like being able to take the time, if they are a little, to sit with them... and talk with them and maybe de-escalate their behaviour if they're agitated... Sometimes that... We're not in a rush to do their care. You're in a hurry because you have no [choice].

Researcher: What about the safety?

Health Care Aide 2: That's bad when you're short staffed because then you're not there to watch, watch them... Some are getting into trouble, fighting with someone down in the corner and you're not there to watch because you just don't have enough staff to do it... Watch them all. And then sometimes then you don't want to cut corners because you don't have the time but sometimes you have to cut the corner and that's where it's difficult because then someone doesn't get a bath that day... Because we have to cut the bath, we don't [have] enough time... Or even with the float. No offense to the float staff because you need them and they're wonderful to have but when they don't know the floor or have never been there before,...

Health Care Aide1: ...it's hard because then you have to go with [the temporary staff member] and help them the whole time so you're almost doing two teams with them or whatever and you're behind. You can't... And then... you're struggling and you're stressed because nothing's being done properly. (Focus Interview 4: 856-920)

The problem of meeting the physical and social needs of the resident with limited staff members was emphasized when the health care aides discussed assisting residents during meals. One health care aide spoke of having four residents sitting at a table but only one could be fed at a time because of lack of staff. Another health care aide described feeding two residents at one time with a spoon in each hand and being concerned not to get the hands mixed up.

There is a topic like feeding, you don't feed one-to-one. You, because there's not enough staff to feed one-to-one... So I tell them what I'm feeding them. But I usually have a spoon in each hand... But I have to keep my hands like this because otherwise they'll go like this... Held crisscross... Yea. Don't want to do that. (Interview 1024:1022-43)

While even fewer staff members were available on the evening shift, health care aides explained that some of their time was taken up with non-resident care tasks such as putting supplies in the residents' rooms. Care activities, such as bathing residents, were time consuming. The result was less time to interact with residents and support them emotionally. One health care aide compensated by calling each resident by name and asking how the resident was feeling.

But I have to clarify, we don't have a lot of time. I don't know about days [but] on evenings [there isn't time] for sitting down with the resident one-to-one because it's a very busy. We're doing, we're stocking the rooms. Some people [are] out of bed. We have baths to do. But my personal thing, I greet everybody by name. Because, uh, that's what I do. And also it's good to say, how're are you doing [name]? And [name] knows I'm here. (Interview 1022:835-42)

One health care aide spoke of feeling powerless within the facility's organizational structure. He/she spoke of how his/her experience of not being able to meet the expectations of either the facility or of other staff.

Health Care Aide: [Only]one [health care aide] on the floor's OK. Work still expected to be.

Researcher: That makes you feel like you have no control?

Health Care Aide: Pretty much. Because we don't, in reality we don't have control of that. Best foot forward, hope things can get [done]. Always know there's going to be something forgotten somewhere and you're going to hear about it the next shift.

Researcher: So it's the pressure from the management down and then it's the pressure from your colleagues when things don't get done.

Health Care Aide: Pretty well it. (Interview1014:57-72)

A number of health care aides commented on the heavier workloads they experienced. They explained this was due to residents requiring higher levels of care than the residents had needed in previous years. For example, more residents were immobile and required being transferred in and out of wheelchairs.

Because I found through the years as I started, I also notice... the more demanding residents that we're getting in. Like when I was younger, there were more walkers [residents who could walk], there were more independent people. Like some of, like my grandfather, that he was pretty simple [to care for]. Now it's like people more with wheelchairs... (Interview 1012:118-23)

Adding to the problem of the higher care needs of the residents was the stress of working longer shifts. The introduction of seven-day schedules compounded the health care aides' emotional and physical stress associated with increased numbers of residents with greater care needs. Some health care aides feared the effect these workloads had on their bodies, perhaps

limiting the number of years they could continue to work as health care aides. One health care aide stated:

Health Care Aide: I have to work 7 days straight. Then I have 2 days off. Back for 3 days. And 2 days off. So it's only 7 and 3, 7 and 3 and only 2 days off between. But it's getting harder and harder. Especially working 7 days straight.

Researcher: What makes it harder?

Health Care Aide: Physically... mentally too... everything maybe because our job. It's really, really... physically and emotionally [demanding]... Seven days.

Researcher: Yes. What about the actual heaviness of taking care of the people?

Health Care Aide: Because like I said, physically. And that, you know we had more [residents who] were able to do things for themselves... Right now I have 20 residents and every single one needs [to be transferred]. Before... they were able to do themselves... like walking... [now]they don't walk. We have to use the machine. We have so many... Before we had like half floor [of residents who could walk], we had like people who were here because it was just like a hotel... They could walk. They were able to [do] everything by themselves. But there was many other reasons. Like I said 10 people. Right now we have 20. (Interview 1015:120-80)

Health care aides also expressed frustration when they were not able to meet the needs of the resident because of the resident's refusal to cooperate with care. A few health care aides spoke of the distress they experienced when residents refused to eat. Other health care aides described feelings of powerlessness when residents rejected both the health care aide and the care the health care aide attempted to provide, as illustrated in the following excerpt:

Bad. Sometimes it's hard when you do [give care to] a resident and you try so hard and you'll go and say, hi, Mrs. So and So, how are you? And you're trying to do their care. And all they say is, get out of here. You're, you're terrible. I hate you. And, and they're just negative, negative, negative. And you're trying so hard to do your best and they're just. And you know it's dementia. You know they

don't mean it and all that but it's very hard because you're trying your best and they're just swinging or get out [of]here you know. And it's, that's hard... Because you're just trying everything you [possibly can]... and it doesn't even matter who it is sometime, whatever staff goes in there, it could be happening to them too. And you try and try and nothing. (Interview1025:688-704)

Another health care aide spoke of the combination of positive and negative emotions he/she experienced when providing care. On the one hand, the health care aide echoed the feelings expressed by the previous health care aide when he/she was not able to meet the care needs of the resident. However, this health care aide also described feelings of personal satisfaction that came from knowing a resident had experienced a particularly good day as a result of the health care aides' caregiving.

Health Care Aide: There is a lady I, I completely feel sometimes I'm like, oh my goodness, I don't know what else I can do? But for some people, just wow, today was just fantastic day, right. But for some people... Like you make them happy. Like somebody, I'm going home and [the resident says] I love you, I love you, I love you and, or, are you going home? When are you coming back? Don't go. Yea. So... that means that person [had a good day]... had a good lunch. She had a good bubble bath. Not just shower, right. Good bubble bath. That, you know... that makes [it]all good.

Researcher: When do you feel not so good?

Health Care Aide: When I'm powerless. The days that I just [see] all my skills, all my knowledge, all my experience, nothing is working. (Interview 1015:383-410)

Finally, a number of health care aides spoke of the distress they experienced when a resident died. Some health care aides had cared for the same resident over a number of years and had developed a relationship with both the resident and the resident's family. Perhaps what was even more difficult was the death of a resident when the resident had no family members or loved ones, leaving the health care aides as the only mourners.

Summary

In this chapter an overview of the model of the health care aides perceiving the resident as a respected person was presented. The overview was preceded by a description of the study sample and followed by a discussion of the contextual conditions in which the health care aides came to understand and interact with the residents with dementia. A summary of the contextual conditions related to the experience of being a health care aide is presented in Table 8.

Table 8.

Contextual Conditions: The Experience of Being a Health Care Aide

Providing competent care

- most HCA's graduates of certified technical college
- HCAs unregulated and unregistered: accountable to managers, residents and their families
- facilities provided some continuing education programs; HCAs had limited knowledge about dementia
- commitment to quality and compassionate care; experience pleasure providing good care

Being a member of a treatment teamPositive Factors

- feeling supported by team members who shared common stressors and offered support; having a good partner helped to get tasks completed

Negative Factors

- conflict with other staff a significant stressor: peers who did not work as hard or share same perception of residents resulting in increased workload for other staff
- staff members who could not speak English well or did not speak English when with residents.
- temporary staff members who did not know residents; regular HCAs providing orientation
- little interaction or support from nurses or other staff
- breakdown of communication between health care aides, nurses, and other team members

Working on a special care unit

- physical space designed to meet needs of residents with dementia
- usually higher staff/resident ratio
- perceived by some as being too institutional

Providing care limited by facility resources.

- limited number of staff members on each shift; fewer staff members on evening shift; time taken for non-care activities
- more than one resident cared for at the same time
- insufficient time to interact with residents and meet residents' social and emotional needs

Providing physically demanding care

- heavier workloads; residents with more complex care needs
- longer shifts; working more days in a row; no control over scheduling
- more residents immobile; residents needing to be shifted in bed and transferred to/from bed

Providing care that caused emotional distress

- HCA's frustration when residents refuse to cooperate with care; rejected health care aide
 - HCA's frustration at not being able to meet resident needs
 - HCA's feelings of loss when resident dies
-

Chapter Six: The Resident Being Perceived as a Person

The health care aide's perception of the resident as a person will be discussed in this chapter as well as the themes associated with this perception. The concepts of personhood and dementia reflected in this perception of the resident will be presented. The chapter will also include a discussion of the facilitators, inhibitors, and consequences associated with this perception of the resident as a person.

The Concepts of Personhood Related to the Resident Being Perceived as a Person

All the health care aides spoke of the resident with dementia as being a person despite the effects of dementia. They refused to objectify the resident or see the resident as merely a passive recipient of care. This perception of the resident reflected three concepts of personhood: a) personhood and the absolute self; b) personhood and the dependency on the regard of others; and c) personhood and person being seen to continue in a personal narrative. In perceiving the resident as a person with an absolute self, the health care aides recognized the resident's unique human qualities and absolute value. They understood the resident as not being diminished as a person because of the effects of having dementia. This concept of personhood encompassed the idea that the person with dementia retained the same values and beliefs he/she had before becoming ill and was not diminished by dementia. When the health care aides perceived the resident as a person, they also conferred the status upon the resident as someone they recognized and respected. This reflected the concept of personhood and its dependency on the regard of others. One health care aide noted:

You can't, they're not an object...You don't get some reward at the end of the day for dressing a statue. You get a reward by that person showing you gratitude because you've focused all of your attention on them. (Interview 1024:885-90)

Finally, the personhood theme of personhood and the person being seen to continue to live out his/her personal narrative was reflected in the health care aide's perceiving the resident as someone who had contributed to society in the past and continued in their life story despite the effects of dementia.

The Themes Related to the Resident Being Perceived as a Person

The variety of ways the health care aides perceived the resident as a person were: a) the resident being perceived as continuing to be a person; b) the resident being perceived as a unique and respected person; c) the resident being perceived as a person continuing to live out his/her life narrative; d) the resident being perceived as a person "who could be me someday"; and e) the resident being perceived as a person who is not a child.

The resident being perceived as continuing to be a person. The health care aides identified the resident as continuing to be a person despite the effects of middle or late-stage dementia. This perception reflected the personhood theme of the absolute person who continued to have the same values and beliefs as before the onset of dementia despite appearing to be a diminished version of his/her former self. The health care aides agreed the resident was not to be defined by his/her disease but instead perceived as an individual who contributed to society when he/she was younger and well. One health care aide described this notion of the resident continuing in his/her life as follows:

This is how we extend their life... how we approach them. How we care for them. How we treat them to be individuals. We don't treat the disease as the person they are. That's not them. You know. Because they might be great people when they were younger, before this disease ever took on. (1019:227-36)

The resident being perceived as a unique and respected person. Consistent with the concept of personhood and the absolute person, the health care aides identified the resident as a

unique person with his/her own personality. This perception also represented the personhood theme of personhood and personality, with the resident understood to be capable of finding meaning in his/her life and influencing others through his/her unique personality. The health care aide had to become familiar with the unique characteristics of the resident and use this knowledge to adapt their approach to the resident, as illustrated in this excerpt:

You have to learn to know this person... It's the person you got to learn first. And then you learn, OK, they've got this dementia, this is maybe what's making them behave this certain way. But they've done this in their life...Well the approach, it's all about their personalities more than about the dementia. I think so. (1011:181-92)

The health care aides recognized the resident as not only being a unique person but also being a respected person despite his/her dementia. The health care aides rejected stigmatizing the resident, believing the resident with dementia deserved the same respect and compassion as people with other chronic diseases. One health care aide stated:

Well, you know, we're taught that, and even if we weren't taught... all people deserve respect. And the person with Alzheimer's because it's no fault of theirs that they have a disease. Their disease is no more of a disease than somebody with MS or polio. This is a disease. They deserve as much respect, if not more, because of their, uh, peculiar affliction. (F3:333-40)

The resident being perceived as a person continuing to live out a life narrative. The health care aides also perceived the resident as a person continuing to live out his/her life story despite experiencing the losses resulting from dementia or living his/her final years on a special care unit. This understanding is reflective of the personhood concept of the person being seen to continue in a personal narrative. This concept of personhood incorporates the idea that the person experiences the story of his/her life in the context of his/her physical, social and cultural world. The status attributed to an older person is the cumulative result of his/her history as well as

aspects of his/her personal life. In understanding the resident as a person living out his/her life narrative, the health care aides observed the resident continuing to be a member of a family with an emotional attachment to his/her loved ones. One health care aide referred to the love residents continued to be capable of showing to their family as evidence of the residents continuing to be family members.

And then... but then the love I can still see that sometime they can still express although they have dementia. As soon as they see the family, they have this glimpse on their face and their eyes is beaming, you know, like beaming... And, and then they're happy. I could see the difference. They're beaming. (1018:282-301)

The resident being perceived as a person “who could be me someday”. Some health care aides perceived the resident as a person “who could be me someday”. Although this perception did not reflect the health care aide being in a particular kind of relationship with the resident, some health care aides were able to identify with the resident and project themselves in the resident’s place sometime in the future. One health care aide commented:

Yea. It's like years, when I look at their pictures, like, oh my, this is... how she was when she was young... And look at her now. She's here in the facility, right... What am I going to be when I am her age? (Interview 1017:643-53)

Some health care aides extended this understanding of seeing themselves in the resident’s place to seeing themselves as taking the place of the resident’s family members.

You get attached to them... And then for some we are their family... Some they, they have no family that come. We become their family... (Focus Interview 4:788-815)

The resident perceived as a person who was not a child. Finally, most health care aides strongly agreed that the resident not be seen as a child. One health care aide even rejected the use of words associated with taking care of children, such as the word, “diaper”. As one health care aide stated:

No. No. And I hate that. I hate that people say that they're going back to their infancy. They're not... It's not at all the same thing. They're, they're requiring help again... where they didn't need it before... But all the things that they've lived through in their life... are what made them who they are. It's like I'm saying, you can't be treating the disease, you have to be treating the individual. (Interview 1011:539-59)

All health care aides agreed that the resident was an unique, and respected person and most agreed that the resident was an adult person who continued to live out his/her life narrative as the same person as before onset of the illness. Some health care aides could even project themselves into the residents' place at some future time. One personhood concept reflected in this perception of the resident was personhood and the absolute person with the health care aides continuing to recognize the unique qualities of the person despite the effects of dementia. This understanding also illustrated the concept of personhood and the dependency on the regard of others. The health care aides, by perceiving the resident as remaining an adult person, continued to confer the status of being a person upon the resident. They also recognized that the resident retained the same personality as when the resident was younger, thus supporting the concept of personhood and personality. Finally, the health care aides appreciated the possibility of the resident having lived a full but demanding life, thus supporting the concept of personhood and the person being seen to continue in a personal narrative.

Facilitators of the Perception of the Resident being a Person

The facilitators of the health care aides' perception of the resident as a person were primarily the personal characteristics of the health care aides. The health care aides' beliefs and values supported seeing the resident as a unique, adult, and respected person and not as an object or as a child. Other personal characteristics that supported this perception of the residents were the health care aides' ability to engage with the residents and their understanding

of the importance of interacting with the resident while recognizing the resident's social and emotional needs.

The health care aides also revealed the characteristics of curiosity and personal initiative. They were curious to find out information about the resident that would give dimension to the health care aides' understanding of the resident. This initiative of the health care aides was revealed in the many ways they gathered information about the resident, either from other staff, from the medical record or from reading life history reviews. Most health care aides spoke of their ability to develop relationships with family members as a means of gathering information about the resident. The health care aides also spoke of how they were able to observe the resident and identify the resident's unique characteristics and personality traits. This included observing the resident as a family member who remained capable of interacting with loved ones.

There were two contextual facilitators that supported the health care aides' gathering information to support their understanding of the resident as a unique person. One was a change in facility policy that permitted health care aides to have access to the medical record and read the resident's social history. The second was the development of life history reviews by various members of the treatment team. These offered a fuller account of the life of the resident. One health care aide described how he/she studied a resident's life history review to gain a better understanding of the resident and the resident's preferences.

I think it [the life history review] is extremely beneficial. We don't have all of the life histories... Well it might help me understand what really irritates them... And if you really study something, you can sometimes discover what they love, sort of the direction that they went in, right. If they were more [of a] stay at home person, liked to knit. Didn't like huge or large social events, chances are they like quiet. They don't, right, like loud noises would trigger them. (Interview 1016:291-300)

Inhibitors of the Perception of the Resident being a Person

One inhibitor of the interpretation of the resident as a person was the workplace culture and the acceptance of terms that had been perpetuated from one generation of staff members to another and which led to the objectification of the residents. Examples include terms used by health care aides that identified the resident by gender, care needs, or transfer method. Residents were referred to as “males”, “feeders”, “walkers” or “Hoyers”. The latter term referred to residents who required mechanical lifting devices to transfer them from bed to chair. Residents were also objectified with the use of a phrase such as “doing her” which a number of health care aides used to refer to providing care to the resident’s body.

Not all health care aides understood the resident as continuing to be the same person as before the onset of the dementing illness. One health care aide spoke of consoling a family member by affirming to this family member that their loved one was a different person than when the resident was well.

And sometimes we do tell our, our resident’s family that [they shouldn’t take their loved one’s illness] so personally. You know the type of people, the type of husband or wife they were, you know. It’s not them. (Interview 1019:253-57)

Although most health care aides perceived the resident as an adult person, a small number saw the residents as children, assuming an attitude of superiority towards the residents. One health care aide described an incident when she shared this observation with other health care aides. It can be assumed that by expressing this interpretation to other staff members, the health care aide may have influenced other staff members to also see the resident as a child.

The health care aides’ efforts to learn more about the residents and thus enhance their understanding of the resident as a unique person were occasionally thwarted. For example,

some medical records on the treatment unit had documents removed in a process called “thinning the chart”. This sometimes resulted in a loss of the record of the resident’s social history. As well, some life history reviews were either not available or out of date. This resulted in the health care aides being left with incomplete information about the resident. As well, some health care aides commented that the information provided by family members at times lacked credibility since it was not consistent with the health care aides’ observation about the resident. One health care aide noted:

There are very few family members who don’t intentionally or otherwise, give you a rose coloured view... because my dad isn’t like this. (Interview1022:302-4)

Finally, although the health care aides all agreed that each resident was a unique and valued person, they frequently spoke of time constraints interfering with their acting on their understanding of the resident as a person. For example, the need to meet deadline sometimes took priority over speaking courteously to a resident, as is reflected in the following excerpt:

Answer you quicker so you can get going. Would you like to go to bed? Well I don’t know. Come on, it’s a simple question here. Like let’s go. We’ve got other work to do, you know. But, and I have been guilty of it where we just, you know what? I’ll come back to you later. There’s other people calling help, help, I need the bathroom or... (Interview1014: 880-91)

Consequences of the Perception of the Resident being a Person

The consequences of the health care aides perceiving the resident as someone who continued to be a person included: a) the health care aides’ feelings of compassion for the resident; b) the health care aides acting in a respectful manner towards the residents; c) the health care aides learning about the resident’s past and using this information during interactions with the resident; d) the health care aides being motivated to provide a high level of

care to the resident; and e) the health care aides adopting communication strategies to meet each resident's unique needs.

There were many instances in the interviews when health care aides spoke of their compassion for the residents. Some spoke of interacting with residents as if the residents were family members or friends. One health care aide demonstrated her understanding of the resident as continuing to be a person by reflecting on what the experience of any person would be if that person was required to live in an unfamiliar place and receive body care from strangers. This health care aide wanted the resident to feel comfortable and welcome on the care unit.

I just talk to them like they're family I guess... Or friends. Like someone that you've known your whole life, right... You want to make them feel comfortable and welcome because they're in a strange place... So how would you feel if someone was ripping off your clothes, not literally, but taking your clothes off that, in your mind, you've met for the very first time... How would you feel? Right. And that's a challenge... It's emotionally [draining when] you come home and you're exhausted... But it was worth it for them. (Interview1016:493-553)

The health care aides demonstrated respect by speaking to the resident during care and responding to the resident as someone who remained capable of making choices. In the following excerpt, the health care aide attempted to put him/herself in the resident's place:

But if we can't communicate with our residents and let, you know, even though they have dementia, they still can tell us if that, or they don't want to be washed right now. Then OK, I'll come back later. But they need that, they need to be respected. They're still humans and I wouldn't want somebody just coming in and throwing a wet cloth on me and doing [care], without any communication. (Interview 1028:471-79)

The health care aides frequently spoke of the importance of showing respect for the resident by learning and using the resident's preferred name. This required the health care aides to make an effort to learn the resident's preferred name, either from reading the medical record

or from family members. However, the health care aide might also learn how the resident wished to be addressed by interacting with the resident as with any person with whom he/she was in a relationship.

Uh, well generally the families have told you by this point... Or it's in their chart somewhere... And sometimes, sometimes you just sort of develop your own little relationship with that resident and maybe they prefer to be called so and so as opposed to being formally addressed. (Interview 1016:653-65)

One health care aide gave an example of demonstrating respect for a resident by explaining problems occurring during the morning routine in a straight-forward manner.

I'm pretty honest, you know. Earlier this morning I couldn't find, uh, a pair of pants to go with the shirt that I'd picked for someone, and I just told the person I was working with, I'm having some trouble, a wardrobe malfunction. (Interview 1004: 698-702)

This same health care aide also referred to showing respect for the resident's personal boundaries. The health care aide spoke of being watchful of a resident's responses, especially when the health care aide examined the resident's body.

A few health care aides referred to the problem of maintaining a respectful attitude towards the resident while working with another health care aide. The health care aides spoke of the struggle to include the resident in the conversation that developed between the two caregivers providing care to the same resident and to ensure the resident felt comfortable in this three way conversation. As one health care aide stated:

With the resident, it becomes a three-way conversation... I think maybe the resident feels kind of, um, neglected. Like doesn't become personal anymore. It becomes like a... It's not between me and resident... a client, it becomes me and my co-worker... You need to stop it but I think it's hard to... Yea. So. But you try to make it work so that the resident feels comfortable. (Interview 1012:566-91)

Another consequence of the health care aides' understanding of the resident as a person was their efforts to learn more about the resident from reading the medical record and life history reviews, information gathering from other staff members, including nurses, and from family members. The health care aides used this knowledge in a number of ways such as facilitating care, calming the resident and bringing pleasure to the resident. An example of a health care aide using information about the resident's background to facilitate care was provided by a health care aide who used her knowledge about the resident's British upbringing to coax him out of bed by promising a cup of tea. Another health care aide spoke of using the names of the resident's wife and daughter to calm the resident during periods of agitation. A third health care aide related in the following excerpt how knowledge of the resident's past life as a farmer was used to bring pleasure to the resident.

Oh he used to be a farmer...So, and he likes if you talk to him about the truck. So his green truck so...So if you want them happy. And some of them, if you want to talk about their family, so they'll be happy. Yea. (Interview 1017:595-605)

Some health care aides found this information useful when trying to understand and cope with a resident's challenging behaviors. Instead of becoming upset with the resident, one health care aide spoke of attempting to understand the resident's behaviors in terms of the resident's life story and present illness.

She loves to kick and kick... everything, you know, like she's very strong. And then, uh, I ask before to one of her family, what did she do before. She loves soccer... she was a soccer [player]. Like, like, she was a, she was in the sports of soccer when but during her younger times. She was a soccer player, like with girls... Even when she's sleeping, kick, kick, kick. Even when you're changing her, she likes to kick, kick, kick. (1018:577-91)

Some of the health care aides considered the possibility of themselves or a member of their family being in the same circumstances as the resident. This insight motivated them to make an extra effort to provide good care, as illustrated in this excerpt:

I always imagine my mom and my grandma or myself and they up here and this is why I [cannot do] shortcuts. This is why I coming home oh so tired. This is why. (Interview1015:1106-09)

Communication strategies. The health care aides' perception of the resident as a valued and respected person led them to make an effort to communicate with residents. This included nonverbal residents and those with challenging behaviors. Most understood that communicating with the resident was a way of showing respect for the resident as well as developing rapport with the resident.

Since each resident was understood to be a unique and respected person, the health care aides spoke of adapting their communication and interaction strategies to suit the abilities and preferences of the resident. One health care aide made a point of saying her approach to residents did not necessarily reflect her personal feelings about the resident but was based on the health care aide's understanding of the resident.

I would like to think that I change the way I talk not so much according to whether I like them or whether I don't like them but according to who they are. If they respond to humour, I might use more of that. If they respond to something else, I might use more of that. (Interview1022:627-31)

Most health care aides spoke of the need to communicate with residents when they provided care to the resident. However, one health care aide pointed out there were residents who preferred the health care aide to remain silent during caregiving. The health care aide recognized and respected this preference of the resident.

Yea. Some of them doesn't like us to talk... Cuz some of them doesn't like noise... So we'll just wash them, get ready and then. (Interview1017:989-1006)

The health care aides frequently referred to the use of nonverbal communication with residents, such as touch, facial expressions, or gestures. One health care aide described how she modified the use of touch when interacting with a male or a female resident. This example illustrated the sensitive problem solving that occurred as health care aides strategized how to best interact with residents.

I mean you might slap a guy on the shoulder say, how's it going because you know he likes that, but you wouldn't do that for a woman. You'd put your hand on her shoulder and you might hold her, sometimes you, some residents like to have their hands held... And if I know that, then I'll hold the resident's hand if it's OK... (Interview1022:928-38)

Most health care aides referred to the need to speak to nonverbal residents. This was especially important during mealtime when health care aides were feeding a resident and therefore spending more time with the resident. Most commented on the importance of speaking to these residents as if the residents were well and still capable of participating in a conversation. All health care aides rejected the idea of interacting with the feeding-impaired resident as if resident were a baby, as illustrated in this excerpt:

Yea. And I try to encourage them. Like some of them won't open their mouth so you're like, here's the spoon. Can you try to have a bit? Um. And the hard part is, with feeding is, you can't like, they're not babies... They're adults. (Interview 1024:1072-75)

Summary

As a result of perceiving the resident as a person, the health care aides agreed that the resident was not an object and should not be defined by his/her disease. In perceiving the resident as continuing to be a person, the health care aides understood the resident to be an

adult and unique person who was worthy of their respect. The health care aides perceived the resident as continuing to live out his/her life story and some perceived the resident as a person they might become at some future time. A summary of the consequences, facilitators, and inhibitors of this interpretation on presented in Table 9.

Table 9.

Summary: The Resident Being Perceived as a Person

Facilitators of this Perception

HCA's beliefs and values

- ability to perceive resident a person continuing in his/her life story
- refusal to define resident by illness; refusal to infantilize resident

HCAs' personal characteristics

- ability to engage with residents; curiosity; initiative; ability to develop relationships with family members
- powers of observation: learns about resident through observing resident

HCA's ability to see self in resident's place

- increasing commitment to good care.

Contextual factors:

- increased access to the medical record and life history reviews.

Inhibitors of this Perception

Workplace culture

- HCA used terms such as "Hoyer" or identified resident by gender or type of care; resident objectified

Not seeing resident as same person as before illness

Seeing residents as children

- resulting in same perception of resident by other staff members

Incomplete or inaccurate life history information:

- medical records "thinned"; social history not complete
- family members not always accurate source of information

Consequences of this Perception

Demonstrating respect for resident

- using resident's preferred name; including resident in conversations when HCA working with other staff members.

Interpreting resident as an adult:

- Interacting with resident as an adult person; rejecting that resident is childlike

Learning about the resident's life story:

- learning from multiple sources

Using resident's life history:

- facilitating care, calming and supporting resident

Recognizing the need to communicate with the resident

Developing communication strategies:

- adapting verbal and nonverbal communication; Communication Enhancement strategies
- speaking to both verbal and nonverbal residents, including residents with challenging behaviors

HCA responding to resident by seeing self in resident's place:

- being committed to giving best care; seeing some residents as if family members
-

Chapter Seven:

The Resident being perceived as a Person in a Relationship with the Health Care Aides

In this chapter, the health care aide's perception of the resident as a person in a relationship with health care aides will be presented. The concepts of personhood and the person with dementia that are related to this perception of the resident will be addressed followed by a discussion of the concept of "relationship" as it is used in this study. This will be followed by a discussion of the themes associated with this perception as well as the facilitators, inhibitors and consequences of the perception of the resident as a person in a relationship with health care aides.

The Concepts of Personhood Related to the Resident Being Perceived as a Person in a Relationship with the Health Care aides.

The interpretation of the resident as a person in a relationship with the health care aides reflected the concepts of personhood and the absolute person, transcendence and personality. In keeping with these concepts of personhood, the health care aides saw the resident not only as an absolute person with innate and unique qualities but as someone possessing an essential inner spirit. The health care aides experienced the qualities and potential of the resident through their physical contact and emotional interactions with the resident within the context of a relationship with the resident. Other health care aides spoke of their relationship with residents being similar to those they experienced with family members. This type of relationship again supports the personhood theme of personhood and transcendence. Finally, this perception of the resident is indicative of the concept of personality and the person with dementia. Instead of the personality of the resident with dementia being described in terms of personality traits, his/her personality was recognized in terms of the resident continuing to be a "meaning maker" who was capable of

experiencing and enjoying events and relationships as these present themselves in in his/her current environment.

The Concept of “Relationship”

This perception of the resident with dementia focuses on the connections or relationships that developed between health care aides and residents as the health care aides fulfilled their caregiving role with the residents. There are various aspects to the term “relationship” as it is used here. The term “accepting relationships” has been used when referring to the relationships between nondisabled individuals and disabled persons, such as those with mental retardation. These relationships are characterized by closeness and affection, with the disability not resulting in the disabled person being stigmatized or discredited (Taylor & Bogdan, 1989). The term, “therapeutic relationship” as set out by the College of Registered Nurses of Manitoba (CRNM, 2011) defines relationship between the nurse and patient as being goal directed to meet the specific needs of the patient. These relationships have five characteristics: 1) respect that supports the dignity, worth, and rights of the patient; 2) trust, with the patient being able to have confidence in the caregiver; 3) empathy, with the caregiver demonstrating understanding of the patient; 4) recognition of the imbalance of power between the caregiver and the patient; and 5) professional intimacy that refers to the physical, emotional, and psychological closeness that exists between the caregiver and the patient. McGilton (2004) observed that the relationships between caregivers and persons with dementia are likely different than those between caregivers and persons who do not have dementia. She also observed that persons with dementia are emotionally and physically vulnerable and the caregiver is therefore in a relationship of power over this person. Persons with dementia have reduced interactional skills such as communication deficits that make them less able to take part in the normal give-and-take of relationships

between non-impaired persons. McGilton and Boscart (2006) asserted that persons with dementia retained the desire to be in relationships with their caregivers and referred to “meaningful relationships” being those that met the needs of the person with dementia. They listed the types of possible relationships between caregivers and persons with dementia as: a) therapeutic; b) surrogate; c) friendly; d) professional; and e) personal and familial.

The Themes Related to The Resident being perceived as a Person in a Relationship with the Health Care Aides.

The themes associated with this perception of the resident were the health care aides’: a) recognizing their relationships with residents; b) perceiving of the resident as a vulnerable person; c) responding to the resident with affection; and d) maintaining a mutual relationship with the resident.

The health care aides recognizing their relationships with residents. All health care aides spoke of the relationships they experienced with residents, often referring to the relationship growing out of the contact the health care aides had with residents during the provision of care. One health care aide stated:

When you are, when you get, you know, when you get in with the resident and you’re doing their care, you’re talking to them. You’re touching, holding their hand and you’re just having like a relationship with them when you’re with them. Like you’re talking all the time and how are you today? Or it’s nice outside. Or, oh you’re we’re going to go for a nice lunch today. Or your family’s going to come here to see you, isn’t that nice? Or, and you just kind of build a relationship with them like when you’re doing their care or when you’re sitting for breakfast with them because you have to feed them. So you sit and you talk, when you’re feeding them their breakfast, you have a relationship then. Stuff like that. (Interview 1025:108-38)

According to the health care aides, these relationships tended to develop spontaneously between health care aides and particular residents. The health care aides described how residents

acted as if they were seeking a connection with the health care aide, with the health care aide responding with affection for the resident, as illustrated in this excerpt:

I don't know what it is. It's just like a feeling you get. Like you just, you just feel so close to that certain resident. And you go there and like some have, some staff will be attached to certain ones more than others and vice versa. And sometimes, and then you go there and sometimes it's funny because you'll have this connection and they'll say, come on Mr. So and So, let's go to the room. And they come with you and it's like they have a bond that they listen to you and they may not listen to somebody else and vice versa. You sort of get this connection and they seem, I don't know, they just seem to be easygoing with and you just sort of feel like a love, like an attachment... And something clicks. I can't. (Interview 1025:615-38)

These relationships between the health care aide and the resident were both therapeutic, with the health care aide supporting the resident's sense of self, and familial with the health care aide expressing an emotional closeness with the resident. The health care aide's relationship with a resident could last throughout the time the resident lived on the nursing unit. When a relationship between a health care aide and resident had lasted over many years, the health care aide experienced grief when the resident transferred out of the unit or died. These health care aides had come to think of the residents as family members.

The health care aides perceiving the resident as a vulnerable person. Health care aides perceived residents as vulnerable persons because of the losses residents experienced as a result of dementia. The residents were also seen as vulnerable because they were dependent on the health care aides for care, could be taken advantage of by others, or needed someone to speak for them in the absence of family members. These perceptions about the residents served as motivation for many health care aides to support the resident and to develop a relationship with the resident, as evident in this excerpt:

Probably because people with dementia, they really, really need help and they also, because they can't do a lot for themselves, although you have to encourage independence depending on the level someone is with their Alzheimer's. And probably too because I think people with dementia, they need a lot of help. They need a lot of protection and they need people looking out for them and their best interest. Because people could easily be taken advantage [of]. (Interview 1026:95-103)

Another reason for the health care aides interpreting the resident as a vulnerable person was the health care aides' recognition of the effect of being in a long term care setting had on the residents. The residents were removed from their familiar surroundings and family members. The health care aides responded by wanting to reach out to the resident and make the resident feel at home and cared for.

And I feel, you know, they've come into this big facility and there's all these strangers and all these people that, and they've maybe come from their home where somebody was taking care of them. I feel, not sad for them, but I feel like I want to make them feel like this is their home. And that we all care about them. And we're here for them. And that way. I don't, I don't know if that describes it. (Interview 1028:123-29)

In these relationships, the health care aides attempted to both understand and support the resident's needs. Some health care aides believed that the resident wanted to trust the health care aide because the resident needed the assurance of having someone to rely on. Health care aides spoke of this relationship of trust with the resident, understanding that the resident had confidence in them and relied on the health care aides for care and protection.

The health care aides responding to the resident with affection. Many of the health care aides felt affection for the residents and some even expressed the concern that the resident feel loved. For example, one health care aide attempted to achieve this through the words she used while providing care. She spoke of how she tried to make the resident feel as if the resident were part of a family.

Researcher: You've been talking about all the words you say while you're giving care. That's important?

Health Care Aide: Just makes the resident feel important, worthy, you know. The more you talk, they feel, uh, like they're being loved and they're being cared for. They feel important. Part of something. A part of family. (1012:814-17)

Maintaining a mutual relationship with the resident. Residents were represented as active agents in their relationships with health care aides. For example, a health care aide recalled residents giving emotional support to the health care aide following the death of the health care aide's friend.

I know I came into work one day, uh, after one of my friends had passed away. And it was an overwhelming feeling because every resident that day that I had was very calm. They had a very calming demeanour. They were very affectionate. And, you know, they'd give you a hug and be like, everything's going to be good. (Interview 1024:459-64)

Another health care aide spoke of the positive experience of having a resident reach out to her. She referred to a resident's unexpected, spontaneous interactions with her that indicated the resident's engagement with her.

It's rewarding just by them being familiar with you and saying a few words to you or holding your hand or looking at you, oh, you come down the hall, or it's just rewarding in those ways. Or they'll be, they'll say something funny even out of the blue they'll say even a little something funny. Or, or you'll be talking and they'll actually be listening and they'll make an answer to something you've said. And then it's like, oh, they are listening. They are, they know, you know, a little conversation with them. (Interview 1025:145-54)

Some health care aides referred to talking to the resident as a friend. Other health care aides spoke of sharing friendly jokes with residents who would then respond. For example, one health care aide recalled calling a resident "Mama" and the resident then calling the health care aide "Mama", saying, "Hi Mama" (Interview 1023:521-25). The same health care aide related

how another resident, who was a former teacher, would “smack” the health care aide on the health care aide’s bottom.

Yes, it’s a friendly joke and then like we have a teacher upstairs. Well she used to be a teacher at [name of] high school. So I’d, yea, she, I guess she was a very strict teacher once upon a time. And, yea, I joke around with her. Hey mama. You’re my mama, she’ll like smack me on the butt. OK. (Interview 1023:515-51)

However, not all interactions between health care aides and residents were positive. One health care aide commented that residents become upset and noisier when health care aides neglected to include the resident in a conversation. Another health care aide spoke of residents being critical and unappreciative of health care aides, causing distress to the health care aide.

While most health care aides related their emotional engagement with residents, a few spoke of maintaining an emotional distance with residents. One health care aide described her strategy for relating to resident with the phrase, “Going with the flow”.

Well in every job [there is] stress. There’s no perfect job... We have our good days and we have our bad days... You know you have some day the residents are bad, someday they’re, you know... so it’s, it just go with the job... Just you know it’s not personal... So you just smile and say thank you and go with the flow. (Interview 1007:117-39)

Another health care aide described how he/she had learned to compartmentalize his/her feelings about residents as a coping strategy. The health care aide recounted that he/she used to think about the residents after going home from work. However, he/she was now able to be sympathetic with residents while at work but not let his/her feelings about the residents invade his/her personal life. This health care aide also said he/she did not become emotional when a resident died.

So, so I can, rather I can and do compartmentalize, I believe the term is,.. I do that probably better than many people, uh, do that. So on one level, I do feel. The first year I worked here, uh, I

dreamt of this place every night... I think I took my job home with me, the expression is... But that hasn't happened for the last 18 years. Um. So I do sympathize with them and give my job to the best of my ability, um, but when I go home, then, then I'm home, you know. (Interview 1022:516-42)

In both of these cases, the efforts to be emotionally removed from the residents acted as measures the health care aides used to protect themselves from either the resident's behavioral outbursts or from feelings of sadness caused by their recognition of the resident's unhappy circumstances and suffering.

Facilitators of the Perception of the Resident as a Person in a Relationship with the Health Care Aides

The primary facilitators of the perception of the resident as a person in a relationship with the health care aides were the health care aides' personal characteristics. One health care aide referred to his/her ability to recognize the phenomenon of a relationship with the resident and to respond:

Yup. Goes both ways. It's a two-way street. (1024:499)

The health care aides' own aging process also facilitated this interpretation of the resident. One health care aide observed that his/her ability to understand residents and relate to them improved as he/she grew older.

I don't know why, but it's as if I understand, as I'm getting older, I think I understand them even better. (Interview 1011:93-95)

Almost all of the female health care aides spoke of their ability to experience feelings of love and attachment with certain residents. This led them to understand the resident as a person with whom the health care aide shared a relationship.

The ability of many health care aides to share their personal experience with residents facilitated these health care aides perceiving the resident as a person in a mutual relationship. For

example, a health care aide related how he/she used his/her experience of having had a poor night's sleep to stimulate conversations with residents during morning care. This usually prompted some residents to share their own experience of how well they had slept. Therefore, both health care aide and resident became united in their common experience of sleeping or not sleeping through the night.

But I'll say, oh man, I had a bad night. And they'll, the residents usually tell me if they slept well or not. Oh yea, even, like even some that don't talk. I says, how was your night? Like they'll, I'm always impressed if I get a little bit of a response. (Interview 1011:1026-30)

Several health care aides revealed their capacity to have insight into the residents' feelings, confirming an understanding of the resident as a person with whom the health care aide shared a relationship. For example, a health care aide observed that some residents need to feel they retained some control in their lives. This health care aide supported the resident through communication strategies such as modifying his/her tone of voice.

I think it's important to always be at a very low tone... sometimes they get frightened and sometimes they feel like... don't tell me what to do. I've been doing this for all these years... So you got to let them know that they're in control...But you just want to help them...to, to do what they need to do... (Interview 1027:1075-86)

Another health care aide spoke of her ability to interpret the resident as a person capable of responsible behavior. In this case, the health care aide spoke of telling a resident he/she did not accept the resident's aggressive behavior while leaving the door open for the resident to continue in the relationship with him/her.

When I said, I'm angry, I leaving... I'll come back later. And then he talk to me again... He change his mind. (Interview 1021:579-87)

Some health care aides identified resident characteristics that facilitated the perception of the resident being a person with whom the health care aides wanted to be in a relationship. For example, a health care aide stated she was more able to relate to a resident who was “easy going”. Yet another was attracted to residents whose personality presented a challenge.

But some of them, like I said, sometimes it’s when they’re, got a little bit of spunk and you want to, you want them to come on over and come and just love you back. (Interview 1025: 658-82)

A contextual facilitator of the resident being perceived as a person in a relationship with the health care aides was the policy implemented by one facility called “Continuity of Care”. This policy permitted the same staff to work with the same residents so that the residents became familiar with the health care aides and could recognize them and learn to depend on them.

Inhibitors of the Perception of the Resident as a Person in a Relationship with the Health Care Aides

As with the facilitators of this perception of the resident by the health care aides, some inhibitors of this interpretation were the characteristics of the health care aides. One health care aide found she was unable to develop a relationship with some residents, making it more difficult for the health care aide to provide care to the resident.

There are some residents where I can’t provide care on them because there’s that, not that connection. (Interview 1024:401-42)

The residents’ cognitive impairment presented another inhibitor of this perception of the resident. One health care aide admitted to preferring interactions with cognitively intact residents who resided on other units. These residents were capable of sharing conversations with her as opposed to residents on the Special Care Unit with whom he/she had difficulty communicating.

I like especially, well when I was... [working in] the personal care [unit]... I loved it there too because they... you can talk to them, right ... because the residents there are still good. It’s just they’re

not independent anymore, right... You can talk to them. They know my name. (Interview 1017:202-17)

A prevalent theme was the attitude of other staff toward residents. The following excerpt illustrates a health care aide's concern and anger when another health care aide refused to take time to complete shaving a resident and meeting the resident's physical and emotional needs.

Or like they're in a hurry. There's another one today. One of the girls was giving a shave to the resident. And the other health care aide just wanted to get it done. One of those [temporary staff members]. And she goes, OK, that's enough shaving, it's done. It's done. Enough of that... We're moving. Let's go. Let's go, she said. And this girl says, no, I'm going to finish this right now... He's enjoying it... He's not fighting or anything.. Let's leave it. Let's just let him have a shave. But the girl wasn't even a regular was saying, let's go. Get it. That's enough shaving, let's go. And it's like... person just hurry and get it done and go sit in the corner... (Focus Interview4:318-43)

Finally, time constraints presented the most pervasive inhibitor of health care aides acting on this perception of the resident and developing relationships with residents with dementia. This factor reduced the opportunity for the health care aides to interact with residents and possibly the quality of these interactions as well.

Consequences of the Perception of the Resident as a Person in a Relationship with the Health Care Aides

The significance of the health care aides perceiving the resident as a person with whom they shared a relationship was evident in the number of consequences associated with this interpretation. These consequences were: a) the health care aides developing strategies to build relationships with residents; b) the health care aides wanting to develop relationships of trust and to be an advocate for residents perceived as vulnerable; c) the effect upon the resident when in a relationship with a health care aide; d) the spontaneous responses of the resident to the health

care aides and the resident feeling empowered in their relationship with the health care aide; e) the health care aides' use of humor and affection in relationships with residents; f) the effect upon the health care aides' attitudes and behaviors as a result of their relationships with residents; g) the communication strategies employed by health care aides as they developed and maintained relationships with residents; and h) the threat to professional boundaries between health care aides and residents resulting from this interpretation of the resident.

Many health care aides saw their job as more than meeting the physical needs of residents. They agreed that an important part of their role was their interaction with residents and the development of relationships with them.

Oh yes. It should be a part of my job... An important part. It helps them feel like they're not, I'm not just there to look after their physical needs... (Interview 1011:1044-54)

A few health care aides said the skills for developing relationships with residents was not taught in school but something the health care aides had learned through trial and error over years of interacting with residents. One commonly used strategy was that, when a health care aide found a particular approach that worked, he/she would share that information with other health care aides.

Yes. It definitely, it's not taught to you via textbook. You have to definitely learn the behaviours of the patients you're working with. And we actually, even with the staff, it's trial and error. Like staff will go try their approach and then they'll recommend it so that it helps you out. (Interview 1024:510-14)

Health care aides revealed different approaches to how and when they began building a relationship with residents. One health care aide commented on the importance of developing the resident's confidence in the health care aide as well as the resident's friendship soon after the resident's admission to the facility.

Right. And it's very important to get this trust and this, uh, friendship for the first two weeks they moved in here. Later, yea, you can do it always. You can, there is always time for, for building friendship. But it's very important from the beginning. You have to be really nice and polite and with manners and treat them like with dignity, right. (Interview 1015:783-88)

One health care aide's approach to building relationships with residents was utilitarian.

The health care aide deliberately set out to develop a relationship with a new resident, especially a resident the health care aide had been warned about. The health care aide would use proactive strategies such as going out of his/her way to introduce him/herself, sometimes shaking the resident's hand and explaining he/she would be providing the resident's care for the next few days.

Many health care aides spoke of developing relationships with residents as an emotional response to the resident. Both male and female health care aides occasionally referred to talking to the resident as they would their mother or someone the health care aide particularly cared about. One health care aide described feeling powerless to meet a resident's needs but found it helped to spend time talking and building trust with the resident. As a result, the resident came to recognize the health care aide and have confidence in him/her. This health care aide described using communication strategies to develop the resident's trust while addressing the resident's unique needs. These included speaking slowly with an "easy voice", sitting, talking with and listening to the resident.

I talk to her just like to my mom... Just like the person I [am] easy with to be around, right. Just someone I really care [for] and I really, uh, like. And she knows me now. So, uh, because she's, she's with us for a few months... with the care too. With the relationship. So before when she started... I feel very powerless... That's all what I could do. I could give her time. Her and myself, I said, we have to build the trust. (Interview 1015:432-49)

Another approach to developing a relationship with a resident combined utilitarianism with compassion. One male health care aide spoke of ways he thought could lead to greater cooperation with the male residents in his care. This health care aide described using touch to facilitate a positive relationship with a male resident. The health care aide intentionally touched the resident on the shoulder when passing or shaking the resident's hand when saying, "Hello," so the resident would become used to the health care aide's touch during care. The same health care aide spoke of using body language such as an open posture and smiling. He found the resident was more willing to allow him to help with personal care.

Like I want someone to feel that I'm being friendly so, you know, you smile with your eyes and open up your body a little bit more... Well because I want them to trust me... And I want them to not see me as a threat. Comfortable in my, easier to deal with certain behaviours to say to someone [I'll] help you to the bathroom. We need to change you. (Interview 1004:430-45)

Most health care aides lamented the limited time they had to interact with residents. They recognized the importance to the resident of the brief time they were able to spend with the resident during caregiving activities.

A consequence of the health care aides interpreting the resident as a vulnerable person was again the health care aides using strategies to build a relationship of trust with the resident. The health care aides were concerned that the residents have confidence in them, and worked to establish the residents' belief in the health care aides' reliability and integrity. As well, the health care aides spoke of the need to be advocates for these vulnerable residents and as well as the need to protect the resident.

Researcher: So what does it mean to be the trusted person?

Health Care Aide 2: Well, see our residents can't always speak for themselves...So we need to be their voice and we need to give them respect and, you know, and we need to do the best for them

and things like that, you know. So I think that's being trusted person. Yea.

Health Care Aide 1: They want to feel safe and stuff.

Health Care Aide 2: Yea. Well I, I'm saying that the trusted person means that we have a responsibility to them as [name] said. We... Make sure all their needs are met. Make sure that they're getting the care that, that they deserve. Safe. (Focus Interview 4:1130-56)

Another consequence of health care aides perceiving the resident as a person in a relationship with them was the influence this perception had on the residents. Some residents came to understand the health care aide as a friend in whom they could rely and someone they had known since being admitted to the care unit.

Several health care aides expressed concern about residents who didn't have family members or others to act in the resident's interest. They spoke of their role as advocates in helping the resident maintain a connection with managers, other staff members and the outside world.

I says, well yes I have to talk for them because no one, especially the ones that don't have family, somebody has to speak up for them for what they want or what they need. (Interview 1011:138-41)

It's a huge part of my job. Some of these people don't have family. That we're the only one they see outside these walls. We're their weather man. We're their, you know, um, we tell them about the world outside. (Interview 1019:1441-49)

One consequence of the health care aides seeing themselves as a trusted person in a relationship with the resident was requesting to be regularly assigned to the resident. For example, a few health care aides spoke of offering to provide care to a resident with whom they had developed a relationship in place of a new caregiver who would be a stranger to the resident.

Yea. They don't know their faces... So of course the float will tell it to me that Mrs. So and So doesn't like me. So I will be the one to

go there... Because they are familiar with me. (Focus Interview 2: 404-39)

Some health care aides reflected on the consequences of the resident not trusting them. The resident wouldn't like the health care aide and the aide would experience more difficulty providing care. In the following excerpt, a health care aide made the observation that if a resident didn't trust the health care aide, the resident would try to protect him/herself and become more aggressive and self-protective.

Well it [the resident not trusting the health care aide] would mean a couple of things. The first thing I mean is that we would have a... tougher time getting our job done because they wouldn't want us. If they didn't trust us, they wouldn't want us to take out off their clothes and wash them and help them to bed. And take them to the bathroom and help them, help them with dinner. Their body language would indicate that they didn't trust us or warm to us because even with Alzheimer's there's body language. (Focus Interview 3: 1002-10)

However, when residents trusted the health care aides, the health care aides described incidents of residents responding to them as partners in a mutual relationship. One health care aide observed that some residents recognized her, even if they didn't recall her name.

You know like that's why I don't introduce myself all the time... Yea. They, they know me already... Not all of them remember me... of course. There's a few that knows my name... But there's a few that will call me whatever names they want me to have, you know... I don't mind. (Interview 1020:947-85)

The health care aides spoke of changes in the resident's behavior as a result of the resident feeling comfortable with them. One health care aide assumed a resident felt safer and less prone to becoming agitated. In the following excerpt, a health care aide spoke of a resident seeming to be content and comfortable in their physical and emotional response to her.

I'm trying to think how they show. Just by being content when they're with you or they may come and touch your hand or they're, you know, when you're talking to them they're not, I mean you get

where they're aggressive too... but they're just sort of, they're just comfortable with you or they laugh with you or they smile with you and things like that. Different, for each different resident, you know, sometimes. (1025:116-24)

One health care aide gave the following example of the consequence of an established relationship between another health care aide and a resident. The resident was redirected from an episode of agitation with the arrival of the health care aide. Both the health care aide and the resident acknowledged their mutual connection and friendship.

Like we have a resident, one of the units I was working on today, and he was really, really, really upset in the afternoon. And we almost were going to call a code on him. But then, um, can I say her name, [name]... Yea. She went over there... Is [resident's name] there and gave like a huge hug and stuff and he kind of perked up when he saw her and then she took him outside for a walk and stuff and that seemed to help a bit for the time... She hasn't been there for a week because of her days off. And she came... he said, where have you been? I haven't seen you in a long time. (Focus Interview 4:1265-84)

The residents' trust in the health care aides as well as the mutuality of the relationship between health care aides and residents was evident in the number of ways the residents demonstrated empowerment. Some residents felt empowered to choose which health care aide with whom the resident would cooperate. One health care aide attributed a resident agreeing to cooperate with her to her knowledge of the resident's life history. The same resident also felt comfortable questioning the health care aide about why he was in the facility.

He usually asks questions... And oh my goodness. Why I'm here. What happened to me? Don't remember this place. Where am I? So he agreed to get up for the tea, right... That's our conversation. That's our communication. (Interview 1015:717-27)

Sharing humor and affection were common themes in the stories health care aides shared about their relationships with residents. A health care aide related that a resident showed he liked her by joking with her as if she was his granddaughter. The health care aide would tell the

resident the jokes her young son had told her the day before and they would laugh together. One day the resident told the health care aide, "I love you," after which the health care aide gave the resident a hug and said, "Thank you".

Like I think I joke more, because I know this resident really likes me, I think likes me like a granddaughter type like, you know... So we joke more with each other about different things. You know I tell him my corny jokes that my 7 year old has told me and things like that, you know, and he always laughs at my jokes, you know, and things. Maybe. Like I don't pick favourites. But I must say, me and him get along really well the way we we're able to communicate even though, you know, he has dementia and he forgets things and stuff like that. But, yea, you know, sometimes yea... Yea, like this person I'm referring to yesterday, I went in his room to answer his call bell and he, I went in there and I said, oh how are you doing? And he looked at me and said, "I love you". And I was like, oh my gosh. So I gave him a hug and I'm like, well thank you. (Interview 1026:494-515)

Other health care aides embraced residents as a way of showing affection. The following health care aide spoke of giving hugs to both the residents she liked and those of whom she was less fond. She saw this as a way of helping residents feel better when the resident was having a bad day but admitted there were some residents who did not feel comfortable with being hugged.

Health care aide: As long as it makes people feel comfortable. Like I'm not going to kiss someone, anything like that. It would just be like holding someone's hand or, or just giving someone a hug when they're sad. Things like that.

Researcher: Right. And do you do that with people you like and people that you're not so fond of?

Health care aide: Yes.

Researcher: Both?

Health care aide: Yes... Because sometimes I think you know what, sometimes someone just needs a good hug, they're having a bad day so they need a good hug or whatever.

Researcher: And how do they react to you when you touch them like that?

Health care aide: Um. Some people they're OK with it and some people not. Like I know, like I know the residents so well so I know who I can... like OK, they're having a bad day but they definitely don't like to be hugged. (1026:613-43)

The personal connection and emotional attachment that developed between health care aides and some of the residents influenced how the health care aides perceived not only the resident but also themselves. For example, some health care aides spoke of feeling affirmed when problematic residents responded to them. One health care aide recalled her feelings of achievement when a resident unexpectedly responded to her.

And then if it works or if I all of a sudden have a resident that never talks, but then talks to me, oh man, then I feel I've really, oh I got that right. (Interview 1011:158-61)

Another health care aide stated that a consequence of her loving relationships with residents was to speak to them as she would to family members. This same health care aide spoke of bringing gifts such as lipstick and soft drinks for residents who didn't have money (Interview 1013: 600-610). However, some health care aides spoke of the need to contain their emotional response to residents. One veteran health care aide stated he/she was still capable of breaking down in tears when considering a particular resident's circumstances.

I'm more empathetic for them. Because you can't, it's hard to explain. Like you can't be, you feel sorry for them. But at the same time you have to show that you're empathetic because if you show sympathy all the time, if it came to our job, you'd probably cry all the time. (Interview 1024:309-13)

Yet another health care aide observed that residents "bring the best out of me". (1019: 580-83). A health care aide, who described herself as shy by nature, observed she became more open and talkative with residents with dementia.

And I think I talk to them. I'm a very... very shy person... So when I'm working with persons with dementia, they don't care if I'm shy or not. So I'm probably more open with them than I am with. (Interview 1016:1068-1075)

While many health care aides spoke of relationships with residents resulting in positive feelings, others told of experiencing distress when their interactions with the resident failed to meet the resident's needs. For example, one health care aide spoke of having negative feelings when she was unable to reduce a resident's episode of agitation.

Negative. I think the negative feelings are...when you're trying to help somebody and they're, they get aggressive and you're, you just want them to know that you're there to help them but... it seems like nothing you do can ease that aggression. (Interview 1028:137-45)

Occasionally health care aides referred to episodes of verbal abuse by a resident. One health care aide told a story about a resident telling the health care aide she was stupid. Later the resident apologized but the health care aide recalled that their relationship was never the same.

Health Care Aide: Yea, yea. Because one day [he]call, one day, one guy [he] told me you are stupid. I didn't talk with, with him anymore. And, uh, he know that... And after one day, he said [interviewee name], can I talk with you? I said, yes. Come tell me. No, I want to, in privacy, and [he] said, he said... I'm sorry... he knows.

Researcher: Now when he said that bad thing to you... then did you stop talking to him?

Health Care Aide: Yea...Yea, because I feel like, uh, I feel like I was good with him and when right away he told me, he told me you are stupid. (Interview 1013:450-79)

The health care aide who chose not to become emotionally engaged with residents used the strategy of "Go with the flow". She used this as a means of coping with a resident's agitated behaviors.

We don't look at it as personally. We just, you know, smile and nod. And sometimes we go with the flow. They say, where's my mother. Is my mother sleeping? Yes, your mother is sleeping. (Interview 1007:250-53)

You know. And just to keep them calm instead of, we don't [say], your [mother] is dead. Because you keep saying that, you know what's going to happen, they're going to escalate and then they're going to escalate. So then we just, you go with the flow. (Interview 1007:263-67)

Communication strategies. Some of the most significant consequences of the health care aides perceiving the resident with dementia as a person with whom they were in a relationship were the communication strategies they used to establish and maintain these relationships. The health care aides' description of communication interactions with residents revealed the following themes: a) recognition of the importance of developing and maintaining communication with the resident; b) developing rapport with the resident; c) finding time to communicate with the resident; d) adapting the three structural aspects of communication; and e) using communication to promote the resident's participation in care activities.

The health care aides generally agreed that using the correct communication strategies with the resident was essential in gaining the resident's cooperation during caregiving. The health care aides referred to the use of both verbal and nonverbal communication. These included speaking calmly to the resident and using facial expressions so that the resident would accept the health care aide approaching them to provide care.

If you're going to go in there and you're going to whip their blankets off and go, we're going to do this right now. Well, you're asking for a fight. But if you go in there and you've explained it calmly and, you know, you're showing the right facial features, um, then chances are you'll succeed. Um. A lot of us, our stuff is nonverbal, you know. They read our emotion.(1024:443-49)

One of the first concerns of health care aides was how to establish rapport with the resident. Only after this was achieved would they be able to gain the resident's trust.

Health Care Aide 2: In the strategy?... Think rapport. Establishing rapport.

Health Care Aide 1: Yea, building trust. Yea. (Focus Interview 4: 1556-69)

A common source of distress for health care aides was not having time to talk with residents. This was especially the case when the resident attempted to initiate a conversation and the health care aide was too busy to take time to respond to the resident. The health care aides spoke of feeling badly about this.

Oh yea. I talk to them. And then even sometimes I'm busy when they starting to talking to me,... I feel like, you know, I feel bad to leave them, you know... like I am busy. Like, you know, I don't know, some of my, my feelings it's scolding me. I don't know why. (Interview 1009:294-305)

Speech language pathologists have identified three structural aspects of interpersonal messages: a) vocal, or modification of voice quality, pitch, loudness and duration; b) linguistic, or the use of words; c) nonverbal or changes in body appearance or movement (Coupland et al., 1988). Although the health care aides were not aware of these designations, one health care aide described using two of the three structural aspects of interpersonal messages The health care aide used eye contact (a nonverbal aspect) while never raising the voice (a vocal aspect) when interacting with a resident. The health care aids also spoke of the need to speak respectfully to the resident and of never using baby-talk.

Researcher: Um. When you're talking with residents, do you ever use baby talk or talk like when you're with children?

Health Care Aide: No. You have to... you have to talk normal... Normally. And, uh, don't raise your voice because they don't like

that... Yea. So talk to them nicely... And eye to eye... Eye to eye contact. (Interview 1006:432-49).

Yet another health care aide described the strategies she used to help the resident experience some control in the caregiving process. The health care aide used a combination of all three structural aspects of interpersonal messages, vocal, linguistic and nonverbal.

Researcher: Right. So you're permitting them to be in control.

Health Care Aide: As much as possible, yes.

Researcher: And, but you're achieving that through your voice?

Health Care Aide: My voice and my actions. My, like the words that I'm saying to them.

Researcher: The words...the voice.

Health Care Aide: Yes.

Researcher: The tone.

Health Care Aide: Letting them know, and well maybe, you know, like... the touch. (Interview 1027:1075-1119)

One health care aide provided an example of how a previous relationship with a family member influenced the way the health care aide interacted with a particular resident. He/she recalled that because a resident reminded the health care aide of his/her deceased parent, he/she modified his/her communication strategies with the resident. The health care aide spoke more slowly, watching for the resident's response by facing the resident. As a result the health care aide was able to establish a relationship with the resident and the resident became calm when he saw him/her (Interview 1021: 418-46).

Another health care aide reflected on how the quality of the relationship with the resident influenced her use of communication enhancement strategies. She took time to be with the resident, thus being able to listen to and observe the resident, while speaking slower so that the

resident could comprehend what was being said. The health care aide's use of this combination of attending behaviors and adapted speech patterns reflected the major components of communication enhancement theory. Again this approach resulted in the resident being more accepting of care from the health care aide.

Health Care Aide: I don't know if I say... like it's just, it's easier to take care of someone that is positive and... that is willing... to accept the help.

Researcher: Yes. And then how, how does that affect what you say or how you act to them?

Health Care Aide: Oh definitely. Definitely. Yea.

Researcher: Yes. You use more words?

Health Care Aide: Sure. But there's some that are easier than, it's easier to convey your feelings towards them.

Researcher: Um. Do you find yourself talking faster or slower?

Health Care Aide: Slower... Yea. Taking more time... I think when I like them, you sit more. You sit closer to them. You're willing to put your hands around them... You sit on the bed with them. You spend, yea. You have your favourites. (Interview 1012:291-326)

Summary

In this chapter, the category of the resident being perceived as a person in a relationship with the health care aide has been presented along with the facilitators and inhibitors of this perception. The consequences of this perception to both health care aides and residents have also been discussed. A summary of these findings is presented in Table 10.

Table 10.

Summary: The Resident Being Perceived as a Person in a Relationship with Health Care Aides

Facilitators of this Perception

Health care aides' characteristics

- ability to recognize phenomenon of relationship
- insight into resident's emotional needs
- work experience
- health care aide's aging
- ability to experience affection towards residents; ability to share personal experiences with residents

Residents' characteristics

- “easy going”; “spunky”

Contextual facilitator

- “Continuity of Care” policy

Inhibitors of this Perception

Health care aides' characteristics

- difficulty relating to some residents
- preference for cognitively intact residents

Attitudes of other staff

- failure to recognize resident as person with unique needs
- impatient to get work done

Time constraints

- prevented health care aides acting on interpretation

Consequences of this Perception

Developing a relationship

- relationship building strategies: utilitarian; compassionate; combination

Response to the resident seen as being vulnerable

- building trust; health care aide as advocate for resident

Residents response to the health care aide

- mutual relationships
- resident empowerment; use of humor and affection by health care aides

Effect on health care aides' attitudes and feelings

- emotional attachment to residents; personal affirmation; negative feelings

Communication strategies

- recognizing need to communicate with residents
- using communication enhancement strategies; modifying structural aspects of speech

Potential for boundary crossing

- compassion and affection versus potential for neglect and abuse
-

Chapter Eight:

The Resident being perceived as a Person who is a Care Recipient

In this chapter the various ways the health care aides perceived the resident as a respected person who was also a care recipient will be discussed. The various concepts of personhood and the person with dementia that are represented in this perception of the resident will be addressed. The facilitators and inhibitors of this perception of the resident will be presented, followed by the consequences of this interpretation. As with previously discussed perceptions of the resident by the health care aides, some of the most important consequences of this interpretation of the resident were the communication strategies adopted by the health care aides as they interacted with residents with multiple care needs and these will also be discussed.

The Concepts of Personhood Related to the Resident being perceived as a Person who is a Care Recipient

In addition to the previously mentioned concepts of personhood, this perception of the person with dementia reflected the personhood concepts of embodiment, language and occupation. The concept of personhood and embodiment is based on the understanding that the person exists in a physical body located in a specific historical and physical context. The gender, race, and ethnicity of the person are critical influences in the development of the embodied person including the manifestation of the person in their old age. The brain, as part of the body, controls all the psychological events of the person's life as well as his/her ability to move and function in the environment. This is the part of the body first impacted by dementia. The health care aides not only provided physically demanding care for the physical body of the resident, but also managed the resident's challenging behaviors that were a result of the disease process affecting the person's brain.

The perception of the residents as care recipients also reflected the personhood concept of personhood and language. The residents depended on their ability to speak and communicate with others in order to express both their personalities and preferences. This concept also encompassed the idea that the ability of the person to communicate with those in his/her environment was dependent on the positive or negative interactions of others, including caregivers. The health care aides made an effort to adapt their communication strategies to meet the various communication deficits of the residents.

Finally, this perception of the resident reflected the concept of personhood and occupation. Occupation is everything that people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their community (productivity). In the *Canadian Model of Occupational Performance* (CAOT, 1997), the person, with a spiritual core and physical, cognitive, and affective components, performs occupations within their physical, social, cultural, and institutional environments. The person is understood to be an active agent in the environment and can choose, organize, and perform meaningful occupations. Meaningful occupations are those that allow an individual to fulfill a goal that is personally important (CAOT, 1997). For residents with dementia, retaining the ability to perform some self-care activities is a meaningful undertaking and helps these residents retain a degree of autonomy and dignity. These activities can include oral care, some aspects of dressing, and feeding themselves. As well, participation in leisure activities that reflect the person's past interests supports that person continuing to live out his/her life narrative. The health care aides recognized the need for the residents to continue to engage in the meaningful activities they remained capable of doing. The health care aides used their

relationship skills and communication strategies to encourage the residents' participation in self-care activities and attendance at leisure programs available within the facility.

The Themes related to the Resident being perceived as a Person who is a Care Recipient

The themes related to the perception of the resident as a care recipient were: a) the resident being perceived as a person with an irreversible disease; b) the resident being perceived as a person with individual care needs; c) the resident being perceived as a person at risk of injury; d) the resident being perceived as a person who can participate in care; and e) the resident being perceived as a person with communication deficits.

The resident being perceived as a person with an irreversible disease. All of the residents receiving care from the health care aides had been diagnosed with dementia. The health care aides often referred to watching residents progress through the stages of dementia beginning with the earlier stage when the resident retained some abilities until the resident's eventual death. They spoke of both family members and caregivers having to accept the inevitable and irreversible progress of the resident's disease.

So you have to be realistic. You hope that they'll be like, oh sweetie, back to what they were, remember what your name is. That's how, I get that. Some of the families think that. But you have to realize it's not [going to happen]. It's way different now. They're changing and they'll continue to change.
(Interview1003:1230-31)

The resident being perceived as a person with individual care needs.The health care aides were able to describe the variety of deficits experienced by residents with dementia, including cognitive deficits, changes in physical appearance, changes in mental status and behaviors, and functional and communication deficits. For example, one health care aide described the behavioral changes and unpredictability demonstrated by the resident with dementia as follows:

Hm. They look like they angry...You can look at the face, they're angry...It's very bad their behaviour... Sometimes they move

faster... Their body language moves faster... Sometimes they didn't know what they're doing... Sometimes they talk in a loud voice and sometimes too slow...Oh, gone. Memory's gone... sometimes they didn't know what they're saying... Sometimes when, when you are in front of him he's good. [But when you come back an hour later, he is agitated.] (Interview 1021:187-243)

Another health care aide observed that a change in a resident's behavior could indicate a physical problem, such as a broken hip (Interview 1013: 327-345). This observation emphasized the role of the health care aide as an observer with the responsibility of reporting changes in the resident's condition to the nurse.

The health care aides tended to view the residents holistically. For example, the health care aides did not describe the resident's lost abilities to dress and groom themselves as isolated phenomena. Instead, they understood these functional deficits in the context of other losses the resident experienced, such as problems with motivation, cognition, and mobility. The health care aides accepted that such clusters of deficits often led to further problems for the resident, such as failure to eat.

Their behaviours. Um. They don't have the same thing we do. Like they don't wake up and go, oh I need to get dressed. Or I'm hungry. Or if you left a dementia patient alone, they wouldn't bathe. They wouldn't dress themselves. They wouldn't like eat. (Interview 1024:256-61)

As well as the variety of symptoms represented by each resident, health care aides also had to negotiate the range of personality types and individual preferences associated with each resident. For example, some residents objected to noise which resulted in the health care aide speaking more quietly to calm the resident (Interview 1025: 241-47). The residents might also show a gender preference for caregivers. One health care aide observed that women objected to male caregivers while some of the male residents couldn't understand why a woman was

undressing him. The same health care aide commented there were residents who preferred to receive care from a health care aide with whom the resident had a special relationship.

Some many of these people with the disease process, you know, they're, they don't want to get washed and [have perineal] care and wash their groins but, but a guy will more often let a guy do them. A woman to a woman. Yea. Depends on the...

And sometimes it's chemistry thing too. You know, like two, one female health care aide might or resident might bond with a particular female. For no reason. Who can say why? But they just like that person. Well that person obviously does their care, right. (Focus Interview 3:1994-199, 2022- 2031)

The health care aides attempted to modify their approach and care strategies to meet the care needs of the residents throughout the day and during different types of care. For example, health care aides described having to deal with the aggressive response of some residents to having their clothes changed or receiving perineal care. Some of these residents would require two or three health care aides working together to provide their care (Interview 1023: 700-726). Other residents with severe dementia often refused to eat, presenting a particular challenge to the health care aide attempting to feed the resident. In each case, the health care aides described the special efforts they made to meet the complex and individual needs of these residents.

Remember there was one lady that's so hard to feed. Who won't open her mouth. But then when I was starting. I said, how can they feed this lady? She wouldn't open her mouth. That was a challenge for me. And then, you know, I talked to her ear... And then she eats. I was so happy. (Interview 1017:1162-70)

Another strategy used by the health care aides to facilitate their interactions with residents during the provision of care was the use of negotiation and collaboration to achieve the resident's cooperation. For example, a health care aide spoke of the importance of making the resident feel that they were making the choices about what happened during morning care (Interview 1020:1102- 04). Others spoke of using "trial and error" to

eventually arrive at an approach that allowed them to provide care for a challenging resident (Interview 1025: 183-97).

The resident being perceived as someone at risk for injury. Residents of long term care units with a diagnosis of dementia represented a risk for injury due to their lack of judgment and insight as a consequence of their cognitive impairment. As part of their role, health care aides were required to anticipate these risks to the resident's safety and prevent residents from becoming injured. The following health care aide spoke of keeping both the resident and the health care aide safe.

If they're on the toilet don't ever leave them because... chances are you'll find them on the floor between the wall and the toilet...

Because you want your number one thing too is safety of yourself and them, you know. You want them to remain safe at all times.
(Interview 1024:985-86, 1015-17)

The resident being perceived as an active participant in care. Some health care aides spoke of encouraging residents to participate in their care. The health care aides recognized that some residents retained the ability to complete some self-care tasks with encouragement and prompting. This understanding reflected the personhood theme of the person and occupation. The theme supported a view that individuals who are perceived as persons are meant to be engaged in meaningful occupations, such as self-care activities.

Health care aides described using gestures indicating brushing teeth or combing hair to promote the resident's participation in morning care (Focus Interview 4: 1457-81). Another explained that asking a resident to help with perineal care reduced the resident's feelings of violation during the provision of intimate care (Interview 1019:1172-1178). The health care aides admitted they did not always have time to let the resident do some tasks for themselves, but most health care aides saw that this type of engagement represented an achievement for both the

resident and the health care aide. One health care aide described her approach in the following way:

If he stops or he forgets, I'll say, do you need a hand? Please. Or he won't say anything but just give you the razor so then I'll just touch it up. So what, you did a great job today. Thank you for your help. (Interview 1014:160-163)

The resident being perceived as a person with communication deficits. Of the many losses experienced by residents with dementia, communication deficits were some of the most problematic for both the residents and the health care aides. One health care aide described the communication deficits presented by the resident as follows:

Oh well a lot of them don't have the ability to talk. We have one gentleman, uh, the odd time he'll be able but he wants to say it but the words don't come out. Like, uh, so you're dealing more with looking at his facial expressions to more. Most of them when they get, they have, they can't speak. (Interview 1011:409-14)

All health care aides were concerned with finding a way to communicate with each resident. One health care aide described communication with a resident was like having a momentary relationship with that resident. Another affirmed that communicating with residents was a necessary part of the health care aide's role. However, as with other deficits experienced by residents with dementia, communication deficits were expressed in a variety of ways. These included any combination of the following: a) hearing deficits; b) attention deficits; c) inability to comprehend what was said; and d) an inability to produce words to express what the resident needed or wanted. The resident's ability to communicate deteriorated over time with some residents becoming nonverbal. Most health care aides recognized that even when the person could no longer speak, he/ she could remain able to hear and understand what the health care aide was saying. Therefore, when presented with a resident's combination of communication

deficits, most health care aides continued to interpret the resident as a person capable of interaction with the health care aide.

So many senses. They still hear you. Just because, you know, they can't speak to you, that doesn't mean they can't hear you...
(Interview 1019:768-70)

Facilitators of the perception of the Resident as a Person who is a Care Recipient

As with the previous perceptions of the residents, the characteristics of the health care aides were the primary facilitators of the perception of the resident as a care recipient. For example, some of the health care aides had experience taking care of family members. All of the health care aides had years of experience working with residents with dementia. They had all observed the progression of losses the residents experienced as the residents passed through the stages of dementia. This experience supported the health care aides' understanding of the resident as a care recipient with a combination of physical and emotional needs.

I don't know what causes it. I just know it's an awful disease...
We've watched enough of them that have gone through it from,
you know, early stages to the very late. (Interview 1019:327-33)

The health care aides were concerned about meeting the individual care needs of the resident. This supported their interpretation of the resident as a unique and respected person who was also a care recipient. The following excerpt illustrates a health care aide's thought processes in attempting to understand the resident's distress:

Oh I have bad feelings when the, when the resident is always like, uh, crying for help although you help them already. And... they still like, like in pain. And it makes you feel so that what does she really want? Why is she like this? Does she miss the family? You know it's like you're not still doing enough at work. Something like that. (Interview1018:645-50)

Most of the health care aides spoke of their affection for the resident. This emotion was often expressed in the health care aides' efforts to provide compassionate care to the residents.

For example, one health care aide spoke of her attempt to address a resident's pain.

So let's say I know that if I touch at a certain spot, that's an achy spot, then it'll be a, because then all of a sudden you're thinking, oh God that hurt, what the heck's going on... So you find out what works. Like sometimes some want to sit on the side of the bed a little longer. (Interview1011:768-73)

Another facilitator of this interpretation of the resident was the respect the health care aides held for the resident. One health care aide spoke of how she intervened when with another staff member was excluding the resident from a conversation.

Researcher: What you told me... you said, when the person is talking to you and not talking to the resident, you put your fingers to your lips to, that they be quiet.

Health Care Aide: Uh, huh.

Researcher: Because it's disrespectful?

Health Care Aide: Maybe because my background, you know, because us we have to respect. (Interview 1013:883-93)

As the health care aides spoke of the care they provided to residents, most revealed having a collaborative approach with the resident. This showed their willingness to understand the resident as a person with whom they could negotiate. The following excerpt illustrates this approach.

I just say their name and I just say, are you OK? Are you ready to get up? And, you know, how was your night? Did you have a good sleep? Um. And then I ask them if they're willing to get ready in the bathroom. If not, then I'll get them ready in their room and then I'll toilet them. (Interview 1024:78-85)

The health care aides who participated in this study were aware that the unique care needs of the residents included the resident's vulnerability and risk of injury. They also

understood that each resident required an individual approach when being redirected as illustrated by the following excerpt.

Health Care Aide: All you have to do is just like, uh, follow them... Maybe they want to go pee. They just cannot tell you. They want to go to the washroom and that's why they're leaving sometimes... Figure out. Yea. Especially when they're wandering. And they cannot, they don't know what to do... They want to tell it but it won't click... And then, then you figure it out. There's something she wants, you know, that she is telling me but she cannot tell.

Researcher: So what do you say to her or how do you get her to come with you?

Health Care Aide: Oh you have to say, oh, hi [resident's name], for example, you know what, it's lunchtime. Would you like to come back? If the patient is not listening to you, would you like to go to the washroom and then you try to say toilet them, they go... They pee. They want to go... They don't want to do something urgent

Researcher: So there are different factors. (Interview1018:1181-1253)

Despite the communication deficits experienced by the residents, the health care aides all understood the importance of communicating with the resident. They understood effective communication to be an essential component of their attempts to meet the unique care needs of the resident. The health care aides also demonstrated an understanding of the resident's changing communication abilities and an acceptance of having to adapt to each resident's unique communication deficits.

Researcher: How did you learn to communicate like this to these residents?

Health Care Aide: I, I think it's just by experience and seeing how, maybe it is with how other... health care aides do it, you might learn something from somebody else how their approach or, you know, years of experience. But it's, I think it's learning. And everyone is different so you might go in with a certain approach and it doesn't work. And then you maybe go with another

approach a different time and see if that works... And it's just by trial and error and experience and seeing how other people do it or, and training from, of course when you're at [name of] facility and they give you say a day of training, education day or whatever, you learn stuff that way too.(Interview1025:183-97)

The contextual facilitator of the health care aides' interpretation of the resident with unique care needs was facility in-services. Although these in-services were brief and only occurred once or twice a year, some of the health care aides found them useful in understanding the experience of the person with dementia (Interview1006: 227-48). One health care aide referred to a specific staff educator who taught her how to approach and communicate with a person with dementia. However, she considered this information as augmenting what she already knew through her own experience and that of her colleagues (Interview 1025: 208-230).

Inhibitors of the perception of the Resident as a Person who is a Care Recipient

Most of the health care aides participating in the study displayed a limited knowledge about dementia. Although this did not appear to interfere with these health care aides perceiving the resident as a person with unique care needs, it may have played a role in the attitudes and behaviors of other staff members with whom the participants worked. For example, the participants described these staff members as being in a hurry to finish providing care without attempting to address the resident's individual needs (Focus Interview 4: 318-43)

Time constraints were another inhibitor to the health care aide being able to act on his/her perception of the resident. Although the health care aides perceived the resident as a person with unique care needs, the pressure of providing care within a limited time often overrode this interpretation of the person. One health care aide described the time constraints of her caregiving routine as follows:

Health Care Aide: Time structure for sure. Because OK, let's say I start my shift. By the time we've got report done and we get to

getting the residents up is probably 20 after 7... So you've got not an hour 45 minutes get everyone up for breakfast... And oh, because if, we usually work in pairs because of the policies here. Like it's they...want you working together.

Researcher: Which is a good thing.

Health Care Aide: Uh, huh. But it, we have about 14 residents, 4 are in a chair or wherever. So it's time consuming...Yes. Yes. Especially on, uh, the floor...There's a lot of immobile residents there. (Interview 1011:287-315)

Inhibitors to perceiving the resident as a person with communication deficits included failure of other staff members to recognize residents' need for environmental supports to promote resident's communication. This was illustrated with examples of staff members who talked to one another instead of to residents during mealtimes or played the television loudly (Interview 1027: 136-41). Another inhibitor to understanding the resident as a person with communication deficits occurred when staff members did not speak English with the English-speaking residents (Focus Interview 4: 1698-1724).

Staff shortages also presented a barrier to acting on the perception of the resident as a person with communication deficits. One health care aide described her dilemma, both during day and evening shifts, in finding time to talk with residents.

And then you've got less staff. Well, yea, well you've got less staff in the evening because they're putting people to bed... Like during the day you have to, spend your day putting people up and down, either you're running to the bathroom, putting them to bed, getting them up. You spend a lot of time with like physical manual tasks to do with the body. But you have less time to spend. But even if you just sit for 5, 10 minutes with somebody and actually look'em in the eye and ask, well how was your day going? Instead of like you're rushing back and forth and you don't have time to... (Interview 1011:257-76)

Consequences of the perception of the Resident as a Person who is a Care Recipient

As a result of their interpretation of the resident as a person who was a care recipient, the health care aides made an effort to address the individual care needs of each resident. Many of the health care aides attempted to do this through providing care that was both individualized and compassionate. For example, the health care aides paid particular attention to how they started their day with a resident. One health care aide described her interactions with a resident when entering a resident's room in the morning.

Health Care Aide: Introduce myself. I knock on the door and say, hi, it's [interviewee name]. Good morning, whatever that person's name is... And call them by their first name... I'm here to get you ready for the day... How are you my friend? Oh I'm fine. How's my friend this morning? Oh she's good... You know.

Researcher: So then you want them to, uh, to sit up and put their feet over the edge of the bed. How would you tell them to do that?

Health Care Aide: Um. I'd say, are you ready to sit up with me at the side of the bed so that we can freshen you up at the top and then we'll do the rest in the bathroom or what did you want to do? Well I'll do whatever you want me to do. All right. So we'll do whatever's easiest. I mean [some] are also visually impaired... a little hard of hearing, sometimes ... You don't want to give 'em too much to think about. You just want to give 'em exact points of what you're going to do.

...Learn that quick because I did that the hard way. Learnt it the hard way. This is not [hard to understand]... often if they can't swing their own legs over, can I help you with that?

Researcher: So before you touch them you ask?

Health Care Aide: Or suggest. I'm going to help you with this... OK. So then you get them to sit up and then as soon as they've already forgotten I was going to help them.

Researcher: Do you speak to them before you touch them?... Do you try to do that all the time?

Health Care Aide: Try and do that every single time. I'm consistent too. I want them to have consistency, I have to. (Interview 1014:534-94)

Another health care aide said she used a soft voice and slow rate of speech and took the resident's hand when approaching the resident. This health care aide looked the resident in the face to say, "Good morning". She also told the resident what day it was and asked about the resident's night. The health care aide would then let the resident get used to her presence by leaving the resident and moving about room, then returning to the resident. This health care aid commented that, "You can't move too quickly to get a positive outcome..." (Interview 1011:697-719).

Other strategies for waking residents included speaking to the resident before touching them, especially those residents with previous war experience (Interview 1014: 645-78). One health care aide turned on the compact disc player as she entered the room so the resident would wake up to music (Interview 1011: 413-54).

A number of the health care aides worked on the evening shift. This shift presented particular challenges for health care aides. Some residents with dementia experience behavioral disturbances in the late afternoon that is sometimes called "Sundowning Syndrome". These residents again required an individualized approach to calm them and help them with their evening routine. Residents with dementia often did not understand when it was time to go to bed and became resistant to removing their clothes and being washed by a health care aide (Interview 1015: 953-63). Finally, there were usually fewer staff members on duty during the evening. One health care aide described her approach in helping a resident get ready for bed that included the health care aide prompting the resident to participate in self-care activities.

Health Care Aide: When I'm doing that I tell them what I'm doing step by step. And, you know, ask them if they can help Ask them if

they can help me wash their face Ask them if they're able to wash their, you know, their privates and what not. Um. Their [perineal] care. So just allowing, just knowing who the residents are and allowing, and the capacity of what they can do.

Researcher: Right.

Health Care Aide: Then allowing them to do that. You know ask them how they're day is. Even if they, they're not able to talk, it's just asking them how their day is. It doesn't mean they're going to talk to you or speak to you. You're still, you know.

Researcher: You think that helps them be able to do more themselves if you talk to them?

Health Care Aide: Um. Yes. Encouraging them. Encouraging them to do more for themselves. Absolutely. (Interview 1019: 1172-90)

Many of the health care aides recognized the need to respond to the resident's unique needs and preferences. Some health care aides referred to the importance of offering choices to the resident. One health care aide commented on this approach as follows:

But sometimes you make them better too if you ask them, do you want to have a shower? Sometimes we give them a shower at night. If they want to have warm bath, you know, it's up to them... And they will answer, yes. And sometimes you, you ask them, you want some apple juice? You give them choices... That makes them happy. And then to make them happy to when you open the closet, give them choices what to wear in the morning. And they still [can make choices], you show them the hangars. (Interview 1018:668-82)

One health care aide described interacting with residents with dementia who complained of sensitivity to noise. This health care aide spoke of learning about a resident's preference for being quiet and for church music from family members. The health care aide therefore adopted a calm approach with the resident as well as supporting the resident's preference to hear church music (Interview 1018: 340-354).

In an apparent deviation from attempting to meet the unique needs and preferences of residents, some health care aides referred to the use of “white lies” to gain the resident’s compliance. Examples of this included telling the resident their daughter (or doctor) was coming so that the resident would agree to get up. One health care aide explained that health care aides cannot force residents to comply and have little recourse except to use of this type of deception to achieve the resident’s cooperation (Focus Interview 3: 685-702).

Mealtime presented a number of challenges for all the health care aides. While some residents were able to feed themselves, others required being fed. Since the health care aides saw mealtimes as social occasions, the health care aides attempted to interact with each resident according to the resident’s remaining cognitive and sensory abilities. Since many residents had poor appetites, the overriding concern was that residents get enough to eat. However, many of the residents were easily distracted by noise in the dining room. One health care aide described how she and her colleagues handled this situation on her unit. She also expressed her satisfaction in finding ways to meet each resident’s unique needs and preferences.

So sometimes what we do is we’ll keep a couple of people that are a little noisy still, not in the dining room and then as the people leave, we bring those in so that, you know, it’s not so bad for the rest...You know what I mean. So everybody’s so individual. And that’s what I love about it because not, everybody’s different. And what works for this person may not work over here. And finding the things that work, that’s my passion. You know finding, you know, you know, finding what works. Yes. (Interview 1027: 954-80)

The health care aides were expected to serve meals to a number of residents with varying levels of independence during the designated meal hour. A common occurrence was a health care aide having to feed more than one resident at a time. One health care aide described her interaction strategies with nonverbal residents who required being fed.

Health Care Aide: I would say, uh, Mr. So and So, I'm, I've got your tray and I'm going to help you eat. I'm just going to grab a chair. We try to have a chair and so you can be at the same level which doesn't always happen. But it's a good thing. It's a good thing... If you could feed one at a time, it's a good thing... Sometimes what we do is we get two people that are feeders and then we'll have their trays there because sometimes we'll have 20 people... But, um, yea, or else we don't have time. So we'll have to, you know, feed this person here while he's making, give him a few minutes, then you feed over here. And so you're not rushing. At least you have two people that you're feeding rather than having their food get cold.

Researcher: Yes. And, um, how much do you talk to somebody when you're feeding them? You talk a lot or?

Health Care Aide: Well, you know, just depends. Some days not. If they're not in a very good mood, you probably don't want to do too much talking. You probably want to just one hand to feed and one to, to hold the other, you know, hold their hand. Because they really like that... You know. They really like when you have a hand either on their [arm], but the hand is nice. They like because they feel somebody's caring for them.

Researcher: And you feel that they eat better when you're in that kind of context?

Health Care Aide: Yes. They do. They do.

Researcher: Do they eat more? Chew better?

Health Care Aide: I think that they're probably more relaxed, more confident, you know. (Interview 1027:877-929)

Although it would seem desirable to maintain verbal contact with residents during meals, some health care aides spoke of their concern that the resident might choke on her/his food. A few refrained from talking to residents while the resident was eating.

A consequence of the health care aides' understanding of the resident as a person at risk for injury was the health care aides' efforts to redirect the resident from injury or becoming lost. The health care could not use force to redirect a resident from harm's way, so many relied on a

combination of verbal and nonverbal communication strategies to convince the resident to turn in another direction. Some spoke of trying to find out what the resident was looking for, such as the bathroom. The health care aides attempted to maintain a respectful tone, using a calm voice and speaking slowly. They used nonverbal communication such as body language, gestures, and occasionally using touch. One health care aide described her strategy for redirecting a resident as follows:

Uh, huh. Usually then I'll go and I'll stand and they say get out. And then I'll, you have to stand your ground and be persistent though... And I'll, I'll talk. You have to be calm again. You can't shy away from, because then they feel, oh I can be aggressive a little and they'll back away... That's not going to work either... So you've got to establish your presence... And they have to know. And usually then I'll try to get them to think of something else. Or talk about something else and then kind of guide them back. (Interview 1011:888-910)

Throughout the interviews, health care aides referred to their efforts to promote the resident's participation in self-care activities, such as the resident washing his/her body, putting on some garments, or retaining his/her ability to feed him/herself. The health care aides not only recognized the importance of the resident retaining these abilities but they also understood that by involving the resident in their own care, the health care aides were contributing to the resident's sense of self (Interview 1014:160-63). As well, some residents became more cooperative when actively engaged in their care (1024: 781-93).

Communication strategies. All of the health care aides perceived the resident as a person with communication deficits as a consequence of the resident's dementing illness. Each health care aide referred to his/her efforts to establish verbal or nonverbal communication with the resident while recognizing that that each resident retained some ability to communicate. The following health care aide referred a resident communicating through his facial expression:

Oh well a lot of them don't have the ability to talk. We have one gentleman, uh, the odd time he'll be able but he wants to say it but the words don't come out. Like, uh, so you're dealing more with looking at his facial expressions to more. Most of them when they get, they have, they can't speak. (Interview 1011:409-13)

The health care aides used a number of strategies to promote communication with residents. One health care aide spoke of the importance of getting to know how much the resident understood. This health care aide found that by asking the resident about the resident's past life, the health care aide was successful in stimulating the resident to speak.

So, so then when you realize that, they no longer can make that conversation, what you do is, you know, you get to know how far and how much, how much they do understand. And you know a lot of them, if you, if you ask them questions from their past, as you know, it's amazing the things they'll tell you. (Interview 1027:338-43)

Another strategy to promote the resident's communication was to mention topics to which the resident was likely to respond. These included references to the time of day, the weather, asking the resident what the resident wanted or enquiring about the resident's well-being (1011:774-91). Another health care aide used music, singing and reading to stimulate residents to speak

Health Care Aide: And music. Music is an amazing trigger.

Researcher: Yes. Yes, it is. Music is a, a wonderful way to get people to sing and to talk and to. Yea.

Health Care Aide: And they're reading skill is for whatever reason is so good even, even like they can read things until very, very late in their Alzheimer's. (Interview 1027:351-58)

The health care aides all spoke of using communication enhancement strategies to facilitate care. These strategies included listening to the resident, pacing speech so that the resident could comprehend what was being said, and giving the resident time to respond. The

health care aides also used the resident's preferred name, and when possible, spoke to the resident in the resident's first language. These strategies were used in combination with visual cues, such as showing the resident the toilet and using gestures. The health care aides also used touch, such as patting the resident on the shoulder. The following health care aides spoke of offering the resident choices to give the resident a sense of control in the caregiving process.

Health Care Aide 1: And I would add, you may [be] offering choices that are like yes, no or this shirt or that shirt.

Health Care Aide 2: Right.

Health Care Aide 1: So that they still get some kind of, what's the word? Get to make, still make some decisions.

Health Care Aide 2: Have some control over their life.

Health Care Aide 1: Control. That's the word. Or even like food too. Like would you like [to] eat your ice cream or...? (Focus Interview 4:1599-1607)

Some health care aides spoke of using a combination of verbal and nonverbal communication to promote the resident's participation in care. This included making the motions of brushing teeth or using a comb. The health care aides also referred to family members leaving notes with frequently used words in the resident's first language. The following health care aides commented on their efforts to engage non-English speaking residents in self-care activities.

Health Care Aide 1: And it helps sometimes to just promote their independence. Because some of them can do these things but it's the brain, you know, just kind of, clicking in, clicking in like here's the comb and then I like sort of make motions so that they put it in their hair. Nights too, like sometimes some of the family member, we have residents who speak a different language like Italian or something.

Health Care Aide 2: Oh, yea, yea.

Health Care Aide 1: And sometimes the family members will have things [notes with words in resident's first language] in their room.

And that sometimes really helps. Like really helps. Yea. (Focus Interview 4:1475-86)

Most of the health care aides spoke of how they had learned to understand the communication cues of severely impaired residents including those who were nonverbal. They understood it was as important to establish communication with these residents as it was with more verbal residents. The health care aides acquired this understanding through their experience with each resident and not through any formal training programs.

Health care aide: Yea. Yea. You can read. We have some residents, you can read their facial expression like an open book. You can tell if you're going to get anywhere with them just by their face alone.

Researcher : Did you learn this?

Health care aide: Yes. It definitely, it's not taught to you via textbook. You have to definitely learn the behaviours of the patients you're working with. And we actually, even with the staff, it's trial and error. Like staff will go try their approach and then they'll recommend it so that it helps you out. (Interview1024:503-514)

The communication cues for severely impaired residents were unique to the individual. The health care aides had learned to be attentive to the resident's gestures and non-linguistic sounds to know when the resident was attempting to express a need for care. The following excerpt illustrates a health care aide's approach to residents who could not speak:

Researcher: What about some, somebody who can no longer [speak]?

Health care aide: Look at their gestures and seek out what they're feeling. You know. And we have a resident, we have a resident that doesn't talk. There are many... Typically makes noises. Specific noises.. .that you, you know... right, and you listen for that. And it's kind of like it's, uh, their own Morse Code. You know, they're talking to you but they're not using words.

Researcher: Yes. You get to know what they mean.

Health care aide: Right. When they're in discomfort, you would know because maybe they're noisier... It's, it could be anything. It could be tapping of the hand, it could be... You just have to know their body language. (Interview 1016:595-627)

Oh they can't speak but you know what you do? You, we, I lotion their hands. I massage their hands. I, you know, just a little bit of touching, you know. (Interview 1007:659-661)

The health care aides used modified communication for residents who had hearing impairments in combination with dementia. They used strategies such as speaking into the resident's more receptive ear, and facing the resident so the resident could see the health care aide's lips moving (Interview 1004:720-34). They tried to keep their voice at a lower pitch, using gestures and standing somewhat to the side of the resident so as not to invade the resident's personal space (Interview 1025:994-985). Some health care aides occasionally wrote notes to the resident but tried to avoid using capital letters that would convey that the health care aide was shouting (Interview 1024:1129-48; Interview 1025:976-85).

Although the health care aides were particularly busy during meal times, they agreed that meals should be a social occasion for the residents. Most of the health care aides attempted to stimulate some conversation with the residents during meals. One health care aide said she told the resident what was on the menu, if the food was hot or cold, or when she was putting milk in the resident's coffee (Interview 1012:664-76). Another health care aide used humor to stimulate conversations, with some residents responding, occasionally by fabricating stories. One resident told about his recent trip to the airport (Interview 1023:566-77). The same health care aide explained that he/she spoke more slowly and clearly so the resident's would understand him/her

and be more likely to reply. (Interview 1023:187-92). A health care aide described her approach to stimulating mealtime conversation as follows:

Researcher: And what do you use to communicate?

Health Care Aide: Everything at my disposal... You, we talked, we touched on some. Voice, a touch, look, a diversion, a picture in my hand, something on my person, something, a lapel on his clothes. Why he's wearing his shoes. Anything at my disposal... Anything which will, it will make him or her feel a little bit better and help me do my job better.

Researcher: And you're extemporizing.

Health Care Aide: Continuously. Continually rather.

Health Care Aide: Everything is ad lib in this job... Because, because you have to go with what you're given and if you're given, if you're given this set of circumstances, then that's your reality for that person... The next person has an entirely different set of circumstances. So you have to kind of, you have to be a mirror I guess, or a sponge, a mirror, something like that... Yea, both. I'm kind of mixing my metaphors there but yea. (Interview 1022:1233-84)

Promoting communication with nonverbal residents during mealtime was even more challenging. One health care aide would name the food she was feeding the resident. If the resident didn't open her mouth, the health care aide took this as an indication the resident didn't like the food (Interview 1012:683-711). Another health care aide would hold the hands of a nonverbal resident, asserting the resident could still hear and understand her. As she stated in the following excerpt, she understood that talking to the nonverbal resident was very important:

Because it's just human communication. It's just human. You can't just, you know, rely on sitting there and trying to feed them. You're having a conversation with another person. (Interview 1019: 1327-1330)

Summary

The perception of the resident as a person who is a care recipient has been presented in the chapter. This has included a discussion of the concepts of personhood associated with this perception of the resident as well as the facilitators and inhibitors of this perception. A summary of these findings are presented in Table 11.

Table 11.

Summary: The Resident Being Perceived as a Person who is a Care Recipient

Facilitators of this Perception

Health care aides' characteristics

- experience taking care of family members; experience working with resident with dementia
- feelings of respect and affection for the resident; concern to meet residents care needs
- willingness to collaborate and negotiate with the resident
- awareness of vulnerability and unique care needs of the resident; resident's risk for injury
- awareness of residents' communication deficits and need to communicate with residents

Contextual facilitator

- facility in-service education

Inhibitors of this Perception

Health care aides' characteristics

- HCA's limited knowledge about dementia

Time constraints; staff shortages

Attitudes of other staff

- other staff members failure to recognize and respond to resident's communication needs

Consequences of this Perception

Health care aides' commitment to compassionate care

- individualized approach to each resident at beginning of day, throughout day, and in evening
- expressing affection for residents

Health care aides' commitment to adapted care to meet individual needs of each resident.

- adopting individual approach to address resident's combination of deficits and abilities
- attempting to respond to residents individual preferences (gender of caregiver; noise)
- redirecting resident from injury

Encouraging residents' participation in care

- offering choices; encouraging resident to do some parts of self-care activities

Adapting care at mealtime

- adapting care to residents' cognitive and sensory deficits; attempting to reduce noise
- responding to needs of more than one resident at a time

Responding to residents' various communication deficits

- developing individualized strategies to promote verbal and nonverbal interactions with residents
 - use of communication enhancement strategies: vocal, linguistic, nonverbal
 - use of verbal and nonverbal communication to promote resident's participation in self-care
 - developing strategies for hearing impaired and nonverbal residents
 - although busy, attempting to promote verbal and nonverbal communication with residents during meal
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Chapter Nine:

The Resident being perceived as a Person with Challenging Behaviors

The purpose of this chapter is to present the perception of the resident as a person with challenging behaviors. The themes of this perception and the concepts of personhood related to this perception will be discussed as well as the facilitators, inhibitors, and consequences of this perception.

The Concepts of Personhood Related to the Resident being perceived as a Person with Challenging Behaviors

The personhood concepts associated with this interpretation of the resident included those of the previous categories. However, the personhood theme of personhood and the regard of others was particularly significant in this perception of the resident. The health care aides continued to confer the status of being a person upon the resident despite the resident's actual acts of aggression or his/her potential for threatening and violent behavior. The health care aides persisted in accepting the resident as a person within the relationships the health care aides had developed with each resident. Another important concept of personhood represented in this perception of the resident was that of the person being seen to continue in a personal narrative. This concept drew on the understanding that the experience attributed to a person in their older years was the cumulative result of their experiences in earlier life. The health care aides attempted to understand the violence of some residents in terms of what they had learned about the resident's earlier experience with violence and previous aggressive behaviors. This information might have been recorded in the resident's life history or told to the health care aides by family members. However, the health care aides occasionally heard the residents speak of the resident's experiences of being abused as a child from conversations with the resident. These

occurrences supported the personhood concept of remembering one's personal history.

According to this concept, a person is not only someone who is perceived by others as capable of recalling his/her past but someone who retains an unconscious understanding of themselves that is consistent with the person he/she was before the onset of the illness. Even when the person cannot recall past events in his/her life, the person retains the inner knowledge of themselves, such as pride or shame and fear.

The Themes Related to the Resident being perceived as a Person with Challenging Behaviors

The themes related to this perception of the resident by the health care aides were: a) the resident being perceived as a person with unpredictable behaviors; b) the resident being perceived as a person who was not held accountable for their actions; c) the resident being perceived as a person who was threatening; d) the resident being perceived as a person who was verbally abusive and e) the resident being perceived as a person who caused harm to others.

The resident being perceived as a person with unpredictable behaviors. Many of the residents the health care aides cared for demonstrated agitated behaviors. The health care aides were always aware that such episodes could escalate with the resident becoming violent, striking out at the health care aide and causing the health care aide possible injury. The health care aides understood that managing agitation was a constant part of caring for the residents on their units. They usually could not predict when a resident might strike out. Despite these behaviors, the health care aides continued to see the resident as a person. One health care aide stated she attempted to put herself in the resident's place.

Health Care Aide: Yea... even though they swear at you, even though they're... like hurting you. It doesn't bug me. It doesn't. No. Because I know they're... sick. You know like they have the sickness that you have to understand them.

Researcher: So they are people. You're responding to them being people. Is that, would that explain [what you said]?

Health Care Aide: Like I respond [to] them as like me. You know what I mean?... Yea, humans. I don't, you know, like I understand that if I'm on their situation, I hope they do the same thing what I do to them. You know like it's, it's. (Interview 1020:1068-83)

One strategy the health care aides had learned to use was recognition of the resident's nonverbal cues. One health care aide observed that residents could become agitated for a number of reasons, such as being constipated (Focus Interview 4:1811-55). Another health care aide recalled that a resident who appeared happy, as occurred when family members visited, could quickly change and become agitated. One possible cause of this sudden change of mood was the anxiety some residents experienced at the end of the day, sometimes referred to as "Sundowning Syndrome".

Health Care Aide: And sometimes I notice when the family, uh, once in a while drop in, uh, and check them. And they're so happy. But then when they leave, they're becoming anxious and they're having Sundowning syndrome. Yea, so it's like up and down their moods.

Researcher: Yea. Hm. The mood is up and down.

Health Care Aide: Up and down. Yea. They're happy and then when their family, where is my family? Like Mr. [name], for example, they usually take him out. He's happy. But when you start changing him he change[s] drastically and we get beaten up sometimes. And now he's taking Versed to calm him down. (Interview 1018:507-11)

The resident being perceived as a person who is not held accountable for their actions. Almost all the health care aides agreed that the residents were not to be held responsible for their aggressive and abusive behavior. The health care aides understood these behaviors as a result of dementia. One health care aide had been hurt by a resident but rationalized that because

this was not the resident's usual behavior, she would treat the resident as she did before the incident occurred.

Health Care Aide 1: I know on our floor I, I don't take it personal. Like I had a gentleman, like he hurt me really hard on Sunday. And it really scared me what he did to me on Sunday. But then I knew, like I know that was something that happens very rarely and I know it's the disease that is doing this. It's not him.

Researcher: But is it frightening? Is it, it was a frightening event and it could happen again. What strategy do you use to go back to that person?

Health Care Aide 1: Same one you used before to, you still approach them the same way you did before.

Health Care Aide 2: Yea. And I just see it as this is just a moment, the disease does some terrible things and I don't know. And I guess the longer I've been in the job, I've learned not to take it personally... (Focus Interview 4:1912-35)

Several health care aides attempted to understand a resident's abusive behavior in terms of the resident's experiences in earlier life. One health care aide recalled that a resident had told her about being abused as a child. The health care aide concluded this part of the resident's life story might explain the resident's current aggressive behavior.

We had one little old lady, she was aggressive. But, but she would talk. Like often you'll be able to get them to talk about their childhood... And she says, well her mother used to always hit them if they didn't do like she wanted. And I'm thinking, OK, well maybe in her mind, like when you've lived with aggression, maybe that's how you become aggressive later on... (Interview1011:591-600)

The resident being perceived as a person who is threatening. When agitated, some of the residents threatened the health care aides with physical harm. One health care aide had learned not to appear frightened when the resident threatened to punch or even kill her. Another

had adopted the attitude that the resident did not mean to threaten her personally but would have become threatening to anyone else in her place.

Yes. It frightened me. Of course somebody, I'm going to punch you or I'm going to kill you. It's, uh, threaten me but I don't show them that I'm, I'm scared... (Interview 1020:722-24)

I don't really, I don't get upset about it... Or angry. Because it's not directed at me... Right. It's just a person. The person that's standing in front of them at the time. Could be anybody. (Interview 1016:565-75)

The resident being perceived as a person who is verbally abusive. A number of health care aides recalled instances of residents being verbally abusive. Although the health care aides tried to discount these episodes, most spoke of feeling hurt by what the residents said. One health care aide described her feelings as follows:

Health Care Aide: Oh yea. This is a lady I'm talking about like she swears at us. She gets mad at us. And like when the daughter, she heard it one time. And you know what, oh I'm sorry [interviewee name], my mom never said that before. She's always been a lady. Her personality changed. It was never like that. You will never hear that word from my mom.

Researcher: When you encounter a person who swears and acts like that, how do you feel towards that person?

Health Care Aide: Sometimes, sometimes, I know because we're just human being, right... It hurts because sometimes they will call you, you fat cow... You're an ugly fat cow. Of course it hurts but then [interviewer name] we're working here, of course, you don't take it personally... Because they are, that's their disease, right. (Interview 1017:767-801)

The resident being perceived as a person who causes harm to others. Incidents of violence were common on the units where the health care aides worked. However, even when residents were physically violent, the health care aides did not blame the resident. Instead, the

resident's behavior was explained as an outcome of the resident's frustration with their circumstances and illness. As one health care aide explained:

I don't think anybody enjoys getting hit. But definitely it's more prominent on our unit with the aggressive agitation. But at the same time you don't, and you can't take it personally because they don't know what they're doing. They're, they know that they're feeling frustration. They can't voice to you that they're frustrated. (Interview 1024:166-71)

Most of the health care aides had experienced physical injury as a result of a resident striking or biting them. One female health care aide related an episode of being hit in the chest by a male resident with whom she had established a friendly relationship. However, the resident had not slept well the night before and struck her when she began to get him up. The health care aide got the assistance of another person and the two provided care to the resident with little communication with the resident. The health care aide said her relationship with the resident was never the same (Interview 1013:511-75). Another health care aide told of the pain she experience after being punched in the eye. She cried and felt frustrated that there was no other staff member available to share the responsibility of caring for this resident (Interview1027:430-467). Violent residents not only presented a threat to the health care aides but to other residents as well. A health care aide told a story of a resident becoming violent in the dining room where there were other residents. He had somehow acquired a knife. The health care aid said her concern was for the safety of the other residents. She and other staff members were able to distract the resident and de-escalate the situation (1019:827-98). In the following excerpt, a health care aid summarizes the dilemma posed by physically abusive residents:

And I know people with dementia, it's a terrible disease. And they can't help their behaviours because it's a terrible disease and what the brain does. But I think it's the aggression from people with dementia. That is really hard. And also, too, the physical labour of it. Because sometimes you're trying to do care on someone who's

very stiff and you're trying to turn them and your back is really sore. Or else you're trying to do the best care on someone and they're turning around and they're hitting you with their fist in the face. I can't count how many times I've been hit. Punched, kicked, spit at. You know things like that. But I just kinda, Okay, it's not their fault. It's not their fault. Okay. You know kind of thing... You have to have that attitude, not take it personally... But it does hurt. And then you, if you have to go to the doctor or go for physio or whatever or the chiropractor, whatever people choose to do. Yea, that I find hard. (Interview1016: 232-59)

Facilitators of the Perception of the Resident being a Person with Challenging Behaviors

The facilitators of interpreting the resident as a respected person despite the resident's abusive behaviors were again the characteristics of the health care aides. Almost without exception, the health care aides accepted that the resident continued to be a person despite his/her agitated, threatening and abusive behaviors. They understood that these behaviors were not within the resident's control but were either a result of the changes to the resident's brain as a result of dementia or some event in the resident's past. The health care aides were more willing to blame the resident's disease than the resident themselves for the resident's challenging behaviors.

During a focus group, some health care aides reflected on the characteristics required of a health care aide when working with unpredictable and potentially violent residents. In the following excerpt, health care aides in a focus group referred to a combination of courage, clinical experience, patience, and tolerance. All of these characteristics would support their interpretation of the resident as someone who continued to be valued as a person despite their challenging behaviors.

Health Care Aide 2: Yes. And I think it's, I think it takes a certain person to, to work there because there has been staff that have picked up a shift or floated and they don't ever want to come back... And because they don't know how to not be OK. They don't know how to work in that kind of environment. Knowing,

and I give them like if they know that they can't personally share the work with a bunch of people because of that, then you have to respect that. Not everybody can.

Health Care Aide 1: No.

Researcher: All right. You guys just have more guts? Or do you have more clinical experience?

Health Care Aide 2: Sometimes I say both. And patience maybe. And more understanding.

Researcher: More patience, understanding, more tolerance.

Health Care Aide 2: Yea, tolerance.

Health Care Aide 1: A big one. (Focus Interview 4:1946-70)

The interpretation of a potentially violent resident continuing to be a person was also facilitated by the feelings of affirmation and pleasure the health care aides experienced as they provided care to these residents. One health care aide commented on the positive feelings she had about working on her unit despite being tempted to work on another floor.

I love my work. Like I love this job. You know I love this, this floor. I've tried so many times to go different floor but, but still I come back here. (Interview1020:743-45)

Many of the health care aides had adopted a philosophical approach to working with residents with difficult behaviors. They understood that they must continue to provide care to these residents. They also understood they were the persons with the most control in their relationship with the resident. Many made the choice to overlook the resident's negative behaviors and continue to interpret the resident as an absolute person who was also capable of positive behaviors.

Inhibitors of the Perception of the Resident as a Person with Challenging Behaviors

One of the inhibitors of this interpretation of the resident was the belief that some residents were deliberately unpleasant. One health care aide agreed that the residents' aggressive behaviors were often a result of their illness. However, he/she observed that some residents had personalities that made them difficult people before they became ill and these unpleasant personality traits explained the resident's unpleasant behaviors now. He/she believed that this was a reflection of the natural human condition, "humans being what they are". This health care aide commented:

The negative feelings though, you know, um, human beings being what they are, there have been a couple of residents on [unit name] over the years who, um, you know, because of their, maybe because of their disease and maybe because of who they are, uh, they would use their abilities to, to be unpleasant... Deliberately so. And a number of companions, not health care aides, had to stop working with these people because they would, they were being, you know, psychologically abused. (Focus Interview 3: 540-52)

A health care aide was advised by his/her superiors not to attempt developing a relationship with an abusive resident (Interview 1022: 691-96). This direction from senior staff did not support the health care aide's interpretation of the resident continuing to be a person. Instead, it appeared to support the belief that an abusive resident was incapable of the same human interactions as more well-behaved residents.

There were other health care aides who did not feel supported by senior staff when they faced abusive behaviors from residents. One health care aide told her supervisors she was afraid of the resident. She was informed she wasn't allowed to be afraid even though she felt she had every right to be afraid. This health care aide also referred to the difficulty the resident's threatening behavior presented as she tried to provide care to the resident.

I was scared of him. I didn't like that I was told that I wasn't allowed to be scared of him. I had actually like saved two staff from being strangled by him. So I felt that I had every right to be scared of him. And it was hard to do care on him because your guard is up... and you know your guard's up. (Interview 1024:565-68)

Consequences of the Perception of the Resident as a Person with Challenging

Behaviors

The health care aides' perception of residents as persons, even as these residents displayed challenging behaviors, continued despite the health care aides' long experience with residents who were agitated, unpredictable, threatening, and verbally and physically abusive. The consequences of this perception of the resident were the health care aides adopting attitudes and strategies that helped them cope with the constant need to manage potential or actual acts of violence. Unlike the other perceptions of residents as persons, the development of verbal and nonverbal communication interaction strategies was not a primary consequence of this perception of the resident. Rather, communication strategies were integrated with the other strategies adopted by the health care aides to interact effectively with agitated, threatening, and abusive residents.

In their interactions with agitated and violent residents, most health care aides adopted the philosophy that the resident was not to be blamed for their behavior. Repeatedly, the health care aides claimed the resident's challenging behaviors were to be understood as a result of the dementing illness or events in the resident's past life. As a result of this belief, the health care aides did not resort to anger when responding to these residents but continued to interact with the residents as respected persons. This philosophy was reflected in the coping strategies the health care aides developed to support them as they provided care to residents who might strike out at

them. For example, one health care aide used humor to overcome the stress of providing care to a threatening individual.

Well I try to, well sometimes I have negative feelings about someone because they are aggressive. But I know it's not their fault. So maybe I just try to stay away because I don't want to be hit or something. But I always, in the back of my head, say, OK, they can't help it. They can't help it, you know. And I try to still kind of, um, have an attitude, OK, they can't help it. And sometimes like, like my way of dealing with stressful situations is being funny. So I try to, you know, lighten up the humour. Try to be funny. (Interview1026:510-28)

Another health care aide also reflected that she could not take the resident's behavior personally since the residents she worked with did not mean to be abusive to her. He/she accepted it was her professional responsibility to provide care to the resident and therefore she adopted the practice of trying to pay less attention to the resident's behaviors (Interview 1019:245-49). Yet another strategy adopted by health care aides was to respond calmly to an abusive resident. For example, when interacting with a verbally abusive resident, one health care aide found it was useful to speak pleasantly to the resident. He/she observed this approach helped to calm the resident and prevented the resident from becoming more agitated.

Researcher: So, but when you have, when you are working with somebody like that who...swears at you, how do you talk to them?

Health Care Aide: No, we talk to them in a nice way. We don't say, you are too...We still talk to them in a nice way because it's more that will, uh, agitate them more... if we, if you calm them down...that helps. (Interview 1017:767-828)

One of the most common strategies used by the health care aides when working with residents they knew to be potentially violent was to adopt an attitude of watchfulness in anticipation of violent behaviors. Residents who were new to the unit and with whom the health care aides were not familiar posed a potential threat to the health care aides. Two health care

aides spoke of defensive strategies they and their colleagues adopted with these new residents.

One strategy was staff warning each other about a new and potentially dangerous resident.

Another was the individual health care aide being constantly aware of the risk presented by some residents.

But then on the new ones [interviewer name] that, if we don't know the resident, new residents that come and they tell us, you watch this guy's pants. This guy bites, something like that. Then we are kinda [watchful] But then once we know them, no, not anymore because we know what to expect. (1017:1056-61)

Health Care Aide: But that said, I mean I'm always with an unknown resident now, it's instinct with me. I always, uh, I haven't been hit. Actually I've never really been hit seriously in this job. I've never been on comp. Uh, I think it's because you assume, if you don't know for sure or if there's a high level of trust, always assume that out of the blue you may get a very big fist in your face. And that assumption is with me a lot.

Researcher: So that is something at the back of your mind?

Health Care Aide: Oh yea...It's in the fore, for me in the front of mind too. I, it doesn't affect how I do my job. But that... that safeguard is definitely there...That's part of the reality. (Interview1022: 742-59)

One way the health care aides remained watchful was to monitor the resident's mood and body posture, to learn to expect the unexpected, and to be prepared to move away from the resident if the resident appeared dangerous. For example, one female health care aide recalled staff members being pleased to hear a resident singing "Jingle Bells" until this health care aide paid attention to the lyrics the resident was singing. She was able to warn her colleagues to withdraw from the resident: he was singing about the ways he would harm them (Interview 1026:848-59).

Another female health care aide spoke of maintaining a space between herself and a resident who was unpredictable. She chose to stand beside instead of in front of the resident and

talked to the resident but remained cautious (Interview 1019:790-816). Yet another female health care aide spoke of the importance of knowing the resident and the resident's patterns of behavior. This health care aide described her habit of remaining vigilant, of leaving the resident but then returning to check on the resident's mood and behavior.

Health Care Aide: ...for my experience, if I'm on that situation... that somebody's kind of agitated or, or on the edge, I said, un, I kinda, you know, I'll come back, you know. Like I know you're in a...good mood right now. I'll be back and check on you. And I do. Like I come back and check on them.

Researcher: So you're telling me that you have an understanding about your patients, your residents. You know them... And that influences how you respond to them.

Health Care Aide: Uh, huh. Yea, understand them. Yea, you know we're human. You cannot be, like I'm not... saying that oh, I love everybody. (1020:747-840)

It was not always possible or safe for a health care aide to work alone when caring for a resident who was agitated. In these circumstances, the health care aide would ask for help from other health care aides. These health care aides would then plan how they would work together to provide care to an agitated or aggressive resident. One female health care aide spoke of how, in such a circumstance, she attempted to establish a calm atmosphere with the other health care aides so the resident would not feel threatened when approached by a number of health care aides at one time.

I just explained everything that I was doing. It ended up we had to have five people do care on him which is already like it's threatening probably to them... I brought it lower I believe because I thought if I just went in there angrily and is like, OK, we're doing this, I don't care, blah, blah, blah, they're not going to react to that. So I was just like, OK, we're going to come in here, we're going to do this. You have to watch your voice. A lot of us don't pay attention. Like we don't realize or we're not in tuned. (1024:582-94)

Some health care aides referred to facility policies that directed them about how they should act when providing care to residents who were abusive. For example, some health care aides were instructed to reduce the amount of time they spent with the resident and provide only basic care. As one health care aide said:

You know... if a resident is very difficult to deal with, then... we're instructed to give just very basic care. To do it as fast as possible. Sometimes we have to use 3 and 4 people if the resident is ... themselves and they're in very bad shape. (Interview 1022:631-36)

Most of the health care aides spoke of having to know how to de-escalate situations when a resident became violent. The following health care aide provided a synopsis of her interactions with an agitated resident.

Health Care Aide: It will be a risk. Yea. We've got a lot of risks.

Researcher: What do you do when somebody's really agitated?

Health Care Aide: When someone's really agitated, you know what, you can approach that person... At the beginning you could tell they're agitated already. Give them space. Give them some time. You don't, don't try and... keep talking to them because that person doesn't want to be talked to right now. Just give them some, give that person some space. And then re-approach... Re-approach, it's always a matter of knowing if that person is going to escalate. And if they start to escalate, it's so hard for them to de-escalate. So let's start at the beginning. If you can see it, step away and give them space, let them calm down. And re-approach when you know that they're calmer. (Interview 1019: 908-26)

The health care aides in this study not only described the attitudes and strategies they had developed to help them interact with violent or potentially violent residents but they also talked about how their response to acts of violence. One female health care aide stated she was frightened by the residents' physically abusive behaviors but she continued to provide care to these residents (Interview 1013:118-130).

Another health care aide drew the comparison of being continually hit by a resident as being in an abusive relationship. She felt she gained some control with such a resident when she was able to work with other staff members (Interview 1027:414-24).

Some health care aides blamed themselves for being injured by residents. One health care aide told the story of being hit by a resident with whom she had a friendly relationship. She leaned over his bedrail to ask, "How are you today?" He hit her in the eye, saying "I got you good". The health care aide blamed herself for being in a position where the resident could strike her (Interview 1011:632-47).

Health care aides spoke of the psychological distress they experienced after being attacked by a resident. One health care aide spoke of not being able to take care of a resident for some time after being bitten by the resident.

Health Care Aide: I was bitten by a resident here who has dementia. Oh at the moment, well it hurt like hell.

Researcher: It hurt your feelings too.

Health Care Aide: Yea. And it did something to my psyche where I couldn't look after him for about 6 months (Interview 1014: 210-20)

However, another health care aide admitted to feeling invigorated when responding to a potentially violent incident. She recalled her feelings as she and other health care aides dealt with a resident who was acting in a threatening manner.

I've, I've really, to be honest, I feel very invigorated. Because it is a challenge for me. It's a challenge as to how we're going to, um, how we're going to approach the situation and how are we going to calm down. How are we going to get this person to? (Interview 1019: 990-97)

Communication strategies. The health care aides modified their verbal and nonverbal communication when interacting with a threatening or violent resident. The purpose of their

communication was usually to calm the resident and prevent the resident from becoming actively aggressive. For example, instead of using communication to engage with a resident, the health care aides carefully monitored their verbal and nonverbal communication to discourage the resident from becoming more stimulated.

One health care aide described how she used this strategy. She adopted nonverbal strategies such as positioning herself in a lower and less threatening position in relation to the resident. As well, this health care aide carefully monitored the resident's nonverbal communication, including the resident's facial expression, to gauge when to leave the resident.

Um. Scary, you know. Like... Yea, it's scares for yourself. But for me, I guess I'm used to them already... You know like I know, I know [what] they're like... I know this person is going to, if I talk so much in front of them they might, they might get mad at me like. So I'm trying my best to position myself where, where they cannot get mad, you know. Like I have to... watch what... I'm saying... [judge] the look of their face... You can tell that's oh, Okay, I should stop now. (Interview1020: 459-74)

In contrast, another health care aide used a combination of verbal and nonverbal strategies when interacting with a potentially agitated resident. In this case, the health care aide chose to speak louder, using gestures and assuming a non-threatening body posture while giving the resident something to hold to forestall the resident striking out at her. With nonverbal residents, he/she listened for sounds or watched the resident's behaviors, such as the resident's hand tapping, that could be predictive of agitation or violence. (Interview 1021: 597-680)

Finally, a female health care aide referred to an entire range of human interactions when she spoke of her experience with a threatening resident. This health care aide described how she attempted to control her speech and facial expression so that the resident would understand she was not threatening to the resident. As the interaction proceeded, she gained confidence to touch and even hug the resident. In the end, she and the resident both wept. This health care aide

summed up her efforts, and those of the other health care aides, by saying she attempted to do her best.

The way I talk? Oh never, never being angry or mad or maybe accidentally he could see my face, maybe he, um, this, in this moment, I'm mad or I'm, my face maybe. But I know you have to do everything what you can to become. And, uh, and make him feel like I'm not an enemy. I'm like his friends and I try to help.... We're not scared to come closer. Uh. Not scared to, uh, hug and touch and, uh, because he has good moments too. He has moments when he cries and we cry with him. So it's, it's not easy to explain but I'm, you do your best. (1015: 563-82)

Summary

In this chapter, the themes of the perception of the resident as a person with challenging behaviors have been presented. The concepts of personhood reflected in these understandings of the resident have also been discussed as well as the facilitators, inhibitors, and consequences of this perception of the resident. A summary of these findings is presented in Table 12.

Table 12.

Summary: The Resident Being Perceived as a Person with Challenging Behaviors

Facilitators of this Perception

Health care aides' Philosophy

- continued to understand resident as a person; didn't blame resident for challenging behaviors; blamed resident's illness or past life events
- found working with residents affirming
- accepted need to provide care to residents despite resident's verbal and physical abuse

Health care aide's experience working with residents with challenging behaviors

- knew residents behaviors would change; resident would change from being challenging to being pleasant

Inhibitors of this Perception

Health Care Aide's Beliefs and Attitudes

- understood some resident's to be naturally unpleasant and deliberately aggressive
- saw little benefit in attempting to develop a relationship with abusive residents

Contextual Inhibitors

- employers discouraged developing relationships with difficult residents
- some health care aides did not feel supported by senior staff when interacting with violent residents

Consequences of this Perception

Did not take resident's behavior personally

- interacted with residents as respected persons despite resident's behaviors

Health care aides developed strategies for interacting with agitated or abusive residents

- adapted individualized approach: use of humor; "tuning out"
- adapted behaviors to reduce resident's agitation
- adopted watchful attitude and defensive strategies: warned other staff; monitored resident's mood; listened carefully to what resident was saying; remained cautious
- worked as a team: HCAs provided care as a team; developed plan to provide care to agitated residents; de-escalated violent situations

Health care aides' response to residents' violence

- frightened but continued to provide care to resident; thought of grandparents in resident's place
- blamed themselves when resident hurt them
- compared situations with repeatedly aggressive resident to an abusive relationship
- experienced psychological distress; took time to return to resident; always returned
- felt invigorated when having to de-escalate a violent situation with a resident

Communication Strategies

- self-monitored verbal and nonverbal communication: attempted to calm resident and not stimulate resident; assumed non-threatening voice tone and body posture
-

Chapter Ten: Discussion and Conclusions

The purpose of this chapter is to provide a review of the theory, “The Resident being Perceived as a Respected Person” and the concepts of personhood that were reflected in the development of this theory. The gaps in the theory will be discussed as well as the conclusions and recommendations resulting from this theory.

Review of the Theory

The purpose of this study was to develop a mid-range theory to describe and explain how health care aides perceive and understand residents with dementia and how these perceptions are reflected in the interaction strategies of health care aides with these care recipients. Strauss and Corbin (1998) define theory as, “A set of well-developed concepts related through statements of relationship, which together constitutes an integrated framework that can be used to explain or predict phenomena” (p. 15).

The theory that has been developed is the result of grounded theory analysis of data collected from individual interviews with 24 health care aides and from four focus groups conducted with some of the same health care aides. The resulting theory is called, “The Resident being perceived as a Respected Person”. The title represents the central category that became evident from the data analysis. This theory is based on the finding that health care aides perceived the resident with dementia as a respected and unique person. When health care aides perceived the resident in this way, they also perceived the resident as a person with whom they were motivated to develop a relationship. As a result of the health care aides’ role as caregivers, they also described and understood the resident as a care recipient with unique needs as well as challenging behaviors. These needs and behaviors resulted from the individualized expression of the cognitive, functional, behavioral and communicative changes resulting from the dementing illness as experienced by each resident with dementia. This perception of the resident was

facilitated primarily by the personal values and beliefs of the health care aides as well as their formal and informal work experience. The inhibitors to the health care aides acting on their perception of the resident as a unique and respected person were the attitudes and behaviors of other staff members, and work stressors such as heavy workloads and time constraints. This perception of the resident occurred in the context of the health care aides' experience which included functioning as unregulated health care providers with limited training, being members of a treatment team while working semi-independently, working with limited resources within a long-term care facility and providing physically and emotionally demanding care to residents with dementia.

When the health care aides were able to act on their perception of the resident as a unique and respected person, they developed and maintained relationships with the residents. The health care aides identified each resident's unique care needs and adapted and modified their care and approach to meet these needs. The health care aides used communication enhancement strategies to encourage communication with the resident which in turn served to maintain their relationships and caregiving activities with these residents. When a resident demonstrated agitated and even violent behaviors, the health care aides attempted to prevent or de-escalate these behaviors. They continued to understand the resident as a respected and unique person who was not held responsible for his/her challenging behaviors which were understood to be a result of the dementing illness.

Nine concepts of personhood were represented in this perception of the person with dementia: 1) personhood and the absolute self; 2) personhood and transcendence; 3) personhood and embodiment; 4) personhood and remembering one's personal history; 5) personhood and language; 6) personhood and personality; 7) personhood and the dependency on the regard of

others; 8) personhood and the person being seen to continue in a personal narrative; and 9) personhood and occupation. The only personhood concept not represented was personhood and mind. Although all residents exhibited varying degrees of dementia, the health care aides refused to define the resident by the consequences of the dementing illness.

This theory gives rise to a number of questions. Are the attitudes, behaviors, and interactions of the health care aides as revealed in this study the most appropriate for addressing the needs of residents with dementia? Perhaps one of the most perplexing questions relates to the origin and source of the health care aides' personal beliefs, values, and commitment to vulnerable persons as presented in this theory. If the health care aide's perceptions of the residents and the resulting interactions with them are indeed beneficial to the resident, how can these be supported? What are the effect of environmental influences such as the supervision of nurses or managers or the organizational structure of the facility upon these perceptions and interactions? What educational supports are necessary for health care aides to address the unique needs of residents with dementia? For example, what educational services are necessary for health care aides to understand how to develop appropriate relationships with residents with dementia, how to appropriately modify care to meet the unique needs of the resident and how to develop communication enhancement strategies to help achieve both of these.

In addressing these questions, the attitudes and behaviors of health care aides and their interactions with residents with dementia as revealed in the data analysis will be compared to the literature about health care aides. This will include the literature about person-centered care. The health care aides' perceptions of the resident and the themes related to these perceptions that became evident through data analysis will provide the framework for this discussion.

The discussion of the environmental influences that impact the perceptions and interactions of health care aides with residents will involve a comparison of the contextual factors of the theory with the literature about health care aides in the organizational structure and the work-life stressors of health care aides. The literature about the essential competencies, formal education and continuing education of health care aides will be used to explore the learning opportunities needed by health care aides to prepare them to address the unique and complex needs of residents with dementia.

Finally, the communication interactions with residents with dementia as described by the health care aides will be compared to the literature about communication and persons with dementia.

Attitudes and Behaviors of Health Care Aides and their Interactions with Residents with Dementia

The primary facilitators of the perception of the resident as a respected person in a relationship with the health care aides and as a care recipient while being a person with challenging behaviors were the personal characteristics, attitudes and behaviors of the health care aides who participated in the study. These included: 1) the health care aides' beliefs and values, including their belief that the resident was a respected adult person; 2) their work experience as well as their personal experience of aging; 3) their dedication to the provision of good care to the resident and their compassionate and empathetic attitudes toward the resident ; 4) their ability to engage with residents and to develop and maintain relationships with the residents; 5) their powers of observation and willingness to learn more about the individual resident with dementia; 6) their ability to demonstrate affection towards the resident and to share personal experiences with the resident; 7) their willingness to collaborate and negotiate with the resident; 8) their

ability to perceive the resident's vulnerability and their insight into the resident's emotional needs; 9) their ability to see the agitated and abusive resident as continuing to be a person and their refusal to lay blame on the resident; and 10) and their willingness to continue to engage with residents who had been abusive and to continue to provide compassionate care to these residents.

There were no specific indicators of the origins of these characteristics or of the influences upon them. For example, the health care aides represented a range of ages, cultural and ethnic backgrounds (Table 4, p. 135). Some health care aides had a college education or vocational training or had partially completed a nursing program prior to training to become health care aides: others had no education other than a high school equivalency (Table 5, p. 135). Their training to become health care aides represented a variety of training programs delivered over a span of years (Table 6, p. 136). The health care aides were employed in worksites with different characteristics. For example, two were comparatively small faith-based facilities while two were large, secular facilities (Table 3, p. 134). However, all of the health care aides shared the same perception of the resident as being a unique and respected person. Osburn (2006) has written that there are a number of explanations why nondisabled persons perceive disabled persons positively and decide to make their lives better. These include personal upbringing, family influences, political and economic ideas, world view, and explicit religious beliefs. None of these factors were explored in the individual interviews conducted with the health care aides in this study. The question about the source of the health care aides' positive beliefs and values was asked during the focus groups but only one health care aide offered an explanation. She stated that how she perceived and interacted with the residents was a result of her family

upbringing. The other health care aides could offer no explanation for their positive perceptions or caring interactions with the residents.

The health care aides were unanimous in their perception of the resident with dementia as continuing to be a person who was not to be defined by their illness. This is the central principle of Kitwood's model of person-centered care (Kitwood, 1990, 1997, 1998; Mitchell & Agnelli, 2015). Kitwood wrote that care for persons with dementia should move away from the medical model which interpreted the individual with dementia in terms of illness and loss. Instead, caregivers should address the unique emotional and psychological needs of the individual. The health care aides in this study refused to interpret the resident in terms of the symptoms of the resident's disease. They not only identified the resident's remaining cognitive, functional, and communicative strengths but encouraged the residents to use and build on these through the health care aides' efforts to encourage the residents' communication and participation in care. These attitudes are compatible with the principles of person-centered care (Kitwood, 1997). They also reflected the fundamental qualities that caregivers should possess if their interactions with the resident were to lead to the resident's "cognitive security" (Pulsford et al., 2016). Cognitive security occurs when the person with dementia experiences meaningful interactions with caregivers and feel their needs are being met. The health care aides' belief that the resident was a unique and respected person was also supported by McKeown et al. (2010) who wrote of caregivers coming to understand the resident with dementia as a "person" and not a "patient". As well, the concepts of valuing people, individualized care and personal perspectives were included in a learning model to support person-centered care developed by Passalacqua and Harwood (2012).

The health care aides also understood the resident to be a person living out his/her life narrative. As a result of this understanding, the health care aides searched for information about the resident's life story to achieve a better understanding of the resident. This activity is supported by McKeown and her colleagues who found that information about the resident's past supported caregivers in seeing the resident as a person and not just a care recipient (McKeown et al., 2010). The health care aides were also able to project themselves into the resident's place, seeing the resident as a person "who could be me some day". Pulsford and colleagues wrote of the need for the caregiver to look beyond their personal perspective and use the resident's frame of reference to acquire an understanding of the resident. They also suggested that having knowledge about the resident's life story and understanding the effects of dementia upon the resident enables the caregiver to interpret the actions of the resident as attempts to meet some need (Pulsford et al., 2016).

The understanding that the resident was not a child was a common theme with all the participants, reflecting their perception of the resident as a respected person. Kitwood (1997) wrote of the negative effects of infantilization of persons with dementia by family and caregivers, referring to this as part of a malignant social psychology that disempowers the person with dementia. Coupland and her colleagues also wrote about the negative consequences upon elders when younger caregivers treated them as children, addressing them with baby-talk or "elder-speak". These behaviors contributed to the phenomenon named *The Communication Predicament of Aging* (Ryan et al., 1995). Instead, the health care aides in this study interacted with the residents as adults, using communication enhancement strategies (Orange et al., 1995; Ryan et al., 1995) to promote their interactions with the residents. These strategies included recognition of each resident as a unique person, attending to the resident's communication

patterns and adapting verbal and nonverbal communication to meet the resident's communication needs.

One of the concepts included in the health care aides' perception of the resident was their understanding of the resident as a person in a relationship with the health care aide. Themes in this category included interpreting the resident as a vulnerable person, responding to the resident with affection and maintaining a mutual relationship with the resident. All of the participants in this study spoke of developing relationships with the residents. The development of relationships between caregivers and persons with dementia has been found to be a central activity in person-centered care (Ericsson et al., 2011; Kitwood, 1997; McGilton, 2004; McGilton & Boscart, 2006; Mitchell & Agnelli, 2015; Passalacqua & Harwood, 2012; Pulsford et al., 2016). Such relationships between nondisabled persons and disabled persons also reflect the concepts related to "humanness", a term used to describe the relationships between parents and foster parents of mentally retarded persons (Bogdan & Taylor, 1989).

Many of the relationships described by the health care aides between themselves and residents developed spontaneously. However, some health care aides deliberately set out to develop relationships with residents to facilitate caregiving. McGilton (2004) observed there is no definition for the relationships that develop between caregivers. McGilton and Boscart (2006) listed a number of types of relationships that can exist between caregivers and residents, including therapeutic, surrogate, friendly, professional, personal and familial relationships. They wrote that in all cases, these relationships should be driven by the resident's needs since the resident is in the position of vulnerability and experiences reduced insight. When the relationship met the resident's needs, it was considered a meaningful relationship for the resident. Many of the interactions and resulting relationships the health care aides described between themselves

and the residents were compatible with McGilton's *Relational Scale* with the health care aides speaking of staying with the resident, as time allowed, adapting their responses to those of the resident, and being able to focus their interactions with the resident on more than just physical tasks. Relationships that was more utilitarian in nature than those that developed spontaneously between caregiver and resident may be outside the parameters of person-centered care since they were not developed in response to a resident's emotional needs and desire for a relationship (McGilton, 2004), but were the result of the caregiver's desire to facilitate caregiving.

The development of these relationships was facilitated by the health care aides searching out the life stories of the residents. They used this information to develop and maintain their relationship with the resident, to promote caregiving through their knowledge of the resident's preferences, to stimulate conversation with the resident and to better understand the cause of the resident's challenging behaviors. This searching for information about the resident also reflected the health care aide's perception of the resident as a person living out a personal narrative. The health care aides gained information about the resident's life story, both from the medical record but also through developing relationships with the resident's family members (Egan et al., 2007). Egan and colleagues found that the development and sharing of life stories that include both happy and sad memories assist caregivers in developing empathetic relationships with residents with dementia and providing them with individualized care. The opportunity for the development of relationships between caregivers and residents that address the specific emotional and social needs of the resident can be promoted when the facility requires that the health care aide set aside time to meet with the resident on a one-to-one basis (Ericsson et al., 2011). However, these opportunities were not available to the health care aides in this study. The health care aides

frequently spoke of the distress they experienced when they did not have the time to respond when a resident spontaneously reached out to them, seeking companionship and conversation.

In speaking of their relationships with residents, the health care aides described the residents as being vulnerable as a result of the resident's losses due to dementia but also because the resident was now living in unfamiliar circumstances. McGilton and Boscart (2006) wrote of the need for caregivers and residents to develop relationships of mutual trust due to the resident experiencing both psychological and physical problems as the result of the move to a care facility. These authors observed that family members felt the relationship between their relative and the caregiver was extremely important, with them seeing the role of the care provider as more than completing a set of defined tasks. As well, family members wanted to develop relationships with caregivers, expecting to work closely with the caregivers and having their knowledge and experience valued. The health care aides in this study spoke of having both positive and negative relationships with residents' family members. However in many cases the family members came to rely on the health care aide to support the family members as they watched their relative progress through the stages of dementia and then to death (McGilton & Boscart, 2006).

Another theme related to the resident being perceived as a person in a relationship with the health care aide was the mutual relationship that existed between the health care aides and residents. McGilton and Boscart (2006) referred to the reciprocity in the relationships between care providers and residents, which they defined as a mutual togetherness with give and take between the health care aides and the residents. The authors suggested that care providers perceived the degree of reciprocity and emotional connection they experienced with resident as a measure of the closeness of their relationship with the resident (McGilton & Boscart, 2006).

The health care aides described their feelings of affection for the residents and how they shared this affection, for example, through the words they used during care. Some health care aides spoke of wanting to make the resident feel that the resident was part of a family. These interactions are compatible with Kitwood's positive person work and the need for caregivers to provide psychological support to persons with dementia (Kitwood, 1997). Pulsford and his colleagues (2016) identified that the caregiver needed to achieve empathy with the person, to develop person-centered attitudes and a compassionate approach and to see beyond the effects of the illness. Cruttenden (2006) has written about the desire of front-line staff to interact with residents as family members and that this desire often grows from the caregiver's informal caregiving experience with family members. Coogle and colleagues (Coogle et al., 2007) have referred to this as surrogate or substitute care, observing that front-line staff found this attachment empowered them in their role as caregivers.

A third perception of the resident was that of being care recipient. This perception reflected the caregiving role which was central to the health care aides' relationships and interactions with the resident. This perception involved the themes of the resident being perceived as a person with an irreversible disease and having individual care needs. In addition, the resident was perceived as a person at risk for injury, a person who was an active participant in care and a person with communication deficits.

The health care aides in this study consistently spoke of their caring attitudes towards residents with dementia and their commitment to providing good care. The health care aides were able to identify the many types of losses the resident experienced as a result of dementia and to accept that the underlying disease process was irreversible. However, they continued in their commitment to providing good care with compassion and empathy. This caring attitude that

has been associated with quality care may be an innate quality rather than something that is taught (Schirm et al, 2000). Many of the health care aides in this study spoke of their previous experience providing care or support to family members, with some of them referring to the residents they cared for as being like their mothers or grandparents. Cruttenden (2006) found that the caring attitudes of front-line staff frequently reflected the relationships these workers had with family members and supported their developing relationships with residents and their family members. Current or previous informal caregiving experience has been associated with higher levels of intrinsic job satisfaction for caregivers, serving to help them cope with the indignities associated with their work. The decision-making latitude given to informal caregivers may contribute to their confidence in managing behavioral problems (Coogle et al., 2007). The health care aides in this study revealed such confidence and insight in the management of residents, particularly when they had to confront the resident who was at risk for injury or exhibited challenging behaviors. However, the health care aides also spoke of the distress they experienced when they could not succeed in meeting the resident's needs. Coogle has observed that caregivers may have feelings of dissatisfaction and distress when they do not experience the same success in their role of paid caregivers as they achieved when they were informal caregivers (Coogle et al. 2007).

In describing their interactions with residents during care, the health care aides again reflected the positive person work associated with Kitwood's caregiving goals of the enhanced personhood and well-being of the person with dementia. These interactions included the health care aides' recognition of the personhood of the person with dementia and their use of negotiation and collaboration as well as their use of humor (Kitwood, 1997). During the interviews, the health care aides revealed the caregiving qualities identified by Pulsford and

colleagues as necessary for the well-being or cognitive security of residents with dementia (Pulsford et al., 2016).

It should be recognized that the some of these attitudes and behaviors of the health care aides might also present a challenge to the maintenance of professional boundaries. Although Kitwood (1997) and Pulsford (2016) identified the need for caregivers to develop empathetic and compassionate relationships with individuals with dementia, these relationships have the potential to cause health care aides to cross the professional boundaries that are part of the caregiver relationship. This boundary crossing occurs when the client's needs are no longer the focus of the relationship and the needs of the caregiver take precedence (College of Registered Nurses of Manitoba, 2011). However, the dilemma for the health care aides in this study was that, because they were the persons providing up to 90% of the direct care and personal contact with residents, they frequently became emotionally attached to these residents. Since they identified the residents as valued but also vulnerable persons, they took on the role of advocates, friends, and even surrogate family members. In these roles, they attempted to provide the emotional and social support they observed was not being provided to the residents by others in the residents' lives. These roles and behaviors may be seen as positive person work (Kitwood, 1997). However, the health care aides were also in the position of greater power in their relationships with the residents. As McGilton (2004) has written, the relationships between caregivers and care recipients are unique because of the cognitive vulnerability of the care recipient. McGilton and Boscart (2006) observed that the needs of the care recipient should dictate the nature of the relationship. Some of the informality that was described by the health care aides when talking about their interactions with some residents may not have been what the resident expected or wanted. In fact, the health care aides may have occasionally resorted to

these behaviors to help them get through a stressful day. In this case, they were meeting their own needs rather than the needs of the resident. However, the health care aides frequently spoke of their deep concern and compassion for the residents and of their efforts to attempt to know the resident well enough to understand what the resident needed or wanted. They also spoke of providing support during times when the resident experienced emotional distress and even crises, as occurred when the resident resorted to abusive behaviors. One of the limitations of the study is that I, as the researcher, was not able to observe these interactions between the health care aides and the residents and to assess the impact of these interactions upon the resident.

There is limited literature available about the interactions between health care aides and residents with dementia in long-term care facilities and few guiding principles specific to these interactions. It might prove potentially harmful to the emotional wellbeing of residents with dementia to discourage the compassionate and caring attitudes and behaviors that were described by the health care aides. However, it is concerning that these health care aides who had limited educational training, especially regarding the provision of emotional support to vulnerable elders, appeared to be the people who frequently provided this support to residents in the absence of family members or more qualified professional staff. The other concerning factor is the limited contact and supervision provided to these health care aides by their nursing supervisors. If nurses had more time to provide this supervision, they would be able to provide direction and support to the health care aides as these workers attempted to address the residents' emotional and social needs as well as their physical needs.

The fourth perception of the resident was as a person with challenging behaviors. The themes related to this perception were the resident being perceived as a person with

unpredictable behaviors who was threatening and verbally and physically abusive but who was not responsible for his/her actions.

Most studies about the agitated and violent behaviors of residents living in long-term care facilities have been directed at organizational responses to residents with agitated behaviors (Cohen-Mansfield et al., 2007; Janzen et al., 2013; Jutkowitz et al., 2016; Leonard et al., 2006; Livingston et al., 2014; Van Vracem et al., 2015). Fewer have been conducted about the experience of front-line staff members who have to cope with this abuse. One such study found that nursing assistants working with residents with dementia could expect to be physically assaulted 9.3 times per month and verbally assaulted 11.3 times per month, with only a fraction of these incidents recorded (Goodridge et al., 1996). Morgan found that front-line staff members were at less risk of being assaulted when working in special care units (Morgan et al., 2005). All of the participants in this study worked on units designated for persons with dementia. They all said that being abused was a natural consequence of their close contact with the residents and of it being “part of the job” (Interview 1022:196). In a focus group, participants described the attitudes required by health care aides when interacting with agitated and abusive residents as courage or “guts”, patience, understanding, and tolerance (Focus Interview 4:1960-66). The last three characteristics are compatible with Pulsford’s caring qualities (Pulsford et al., 2016)

The accepting attitudes as well as the behaviors of the health care aides as revealed in their descriptions of their interactions with these residents were echoed in the literature about training programs for front-line staff interacting with agitated residents with dementia. In a systematic review of randomized clinical trials of non-pharmacological interventions to reduce agitated behaviors (Livingston et al., 2014), the recommended strategies were those that emphasized staff communicating with people with dementia and which helped staff members

understand and meet the needs of the residents. In another study about teaching staff to recognize the nonverbal cues of potentially aggressive residents (Chrzescijanski et al., 2007), it was found that staff frequently ignored these cues and did not understand anger as a legitimate response of the resident. The health care aides in this study spoke of their continuing efforts to communicate verbally and nonverbally with residents to reduce the resident's distress and agitation. They also spoke of their need to be continually observant and aware of changes in the resident's behaviors. Many spoke of understanding the resident's aggression as a natural response to the resident's frustration with the changes resulting from his/her disease as well as his/her life circumstances. The health care aides agreed that the resident was not to be held responsible for these behaviors. In this belief, the health care aides are supported by researchers such as Snellgrove and her colleagues who ascribed the agitated behaviors of residents with dementia to the unmet needs of these individuals (Snellgrove et al., 2015). The relationship of aggression with the unmet needs of residents was also identified by Cohen-Mansfield et al. (2007). Leonard et al. (2006) found a relationship between these aggressive behaviors and depression, delusions, hallucinations and even constipation.

In accepting that the residents were not to be held responsible for their aggressive behaviors, the health care aides were still left with the need to cope with and manage these behaviors. The literature provides direction for facilities, care teams and nurses to address the agitation and violence of residents. However, most of these interventions are beyond the health care aides' scope of practice to implement on their own initiative. According to the literature, there are two possible avenues for addressing the agitated and violent behaviors of residents with dementia. These are either pharmacological or non-pharmacological interventions. Azermai (2014) wrote that, whenever possible, non-pharmacological interventions should be used to

reduce or prevent aggressive behaviors. Azermai suggested the two most effective of these were exercise programs and person-centered care. Many studies have been conducted on the efficacy of non-pharmacological interventions (Cohehn-Mansfield et al., 2007; Janzen et al., 2013; Van Vracem et al., 2015). Jutkowitz and colleagues (2016) undertook a review of the literature about non-pharmacological interventions and were not able to find conclusive evidence about the effectiveness of any of the suggested techniques.

When pharmacological and non-pharmacological interventions do not prevent a resident's agitated or violent behaviors, professional caregivers, such as nurses, may turn to the use of chemical, environmental, or physical restraints. However, the literature about the use of restraints and the policies that have been developed to guide staff in their use are clear that restraints should be used as a last resort. They must be used with the permission of the resident or the Substitute Decision Maker and applied by staff trained in their use (College of Nurses of Ontario, 2009; Ontario, 2001; WRHA, 2015). Cheung and Yam (2004) wrote that the use of restraints without the permission of the resident is morally unjustified. The ethicists, Hughes and Common (2015) wrote that all such interventions must be used with compassion, honesty, integrity and prudence.

Educational programs have been developed to help front-line staff deal with agitated or violent residents. These include programs that teach caregivers how to develop sensitivity to the nonverbal communication of residents (Magai, Cohen, & Gomber, 2002) and that help staff develop communication skills to increase the resident's feelings of wellbeing (McCallion et al. 1999). Only two health care aides in this study spoke of attending an educational program to help them deal with actively violent residents. This was the *Non-Violent Crises Intervention* program offered through the Winnipeg Regional Health Authority. This program teaches

techniques a caregiver can use to de-escalate a violent situation or to physically respond when attacked by a resident (Crisis Prevention Institute, 2016; WRHA, 2016).

In their study about the strategies used by Certified Nursing Assistants (CNAs) to prevent and manage the violent behaviors of individuals with dementia (Snellgrove et al., 2015) the authors found the overriding theme from the responses of the CNAs was “Putting the Resident First”. These CNAs, who had no training in managing violent behaviors, found that if they got to know the resident well, they could identify the signs indicating when the resident was about to become agitated. The CNAs also spent quality time with the resident to prevent the resident from becoming bored, a common trigger for agitated behaviors. The health care aides in this study spoke of spending as much time as they could in developing caring relationships with the residents and promoting social interactions with residents.

Environmental Influences Impacting Health Care Aides

In the theory resulting from data analysis, the inhibitors of the health care aides’ perception of the resident as a respected person included environmental factors such as: 1) the work-place culture that permitted the use of objectifying terms and attitudes towards residents with dementia; 2) the attitudes and behaviors of other staff members who did not share the same perception of the resident; 3) heavy workloads and time constraints; 4) the health care aides’ lack of knowledge about dementia; and 5) the belief of some participants that some residents were unpleasant by nature, with little to be gained by developing a relationship with a potentially aggressive resident.

Many of these inhibitors, such as conflict with other staff, heavy workloads, shortage of staff and time constraints, can be categorized as work related stressors (Aitken, 2005; Bangerjee, 2012; Chappell & Novak, 1992; Cruttenden, 2006)

It can be assumed these stressors interfere with health care aides having the time, energy, and motivation to interact with residents as respected persons. Chappell and Novak (1992) defined stress as a lack of fit between the needs of the individual and the environment, with the numerous work-related stressors experienced by health care aides preventing them from experiencing job satisfaction and quality of work life. Aitken (2005) estimated that a nursing assistant in a long-term care facility in British Columbia moved up to two thousand pounds per day when they lifted and transferred residents. Nurses interviewed in focus groups described the work demands of nursing assistants as “trying to please the nurses, the management, and the families. It’s overwhelming” (Schirm et al., 2000, p. 287). Disorganization of work flow and frequent interruptions were observed to result in less time for health care aides to interact with residents (Mallidou et al., 2013). Health care aides were also asked to perform numerous activities such as clerical and non-resident contact tasks that took their time away from providing direct care to residents and interacting with them (Cummings et al., 2013). Health care aides also experienced relatively low pay and conflict with residents and their family members and co-workers (Browne & Braun, 2008; Morgan et al., 2005).

The work culture of the health care aides is also stressful, again draining the personal resources of health care aides that could otherwise be directed to meeting the emotional and social needs of residents. Aitken (2005) wrote health care aides are undervalued in the medical model of healthcare implemented in most long-term facilities. In focus groups conducted by Schirm and colleagues (2000), nursing assistants observed the difference in status between themselves and licensed nurses resulting in them feeling undervalued. Banerjee and his colleagues (2012) explored the concept of “structural violence” or the indirect forms of violence that are built into social structures in the Canadian long-term care workplace. Other researchers

found that Canadian front-line health care workers were poorly trained, experienced heavy workloads, rigid work schedules, low autonomy and status, and exposure to verbal and physical violence from residents and their family members (Banerjee, 2012; Estabrooks, et al., 2012). In Aitken's observation, the support of fellow team members was discouraged by supervisory staff due to the perception that health care aides were wasting time talking to each other. Aitken believed that such interactions between staff members were necessary to strengthen workplace relationships since many of these workers were immigrants from different cultures with English as a second language.

Health care aides have been observed to work with greater autonomy than they have done in the past and with limited contact with other levels of staff (Aubrey et al., 2013; Banerjee et al., 2012; Cruttenden, 2006; Cummings et al., 2014; Schirm et al., 2000). In their responses to the interview questions for this study, the health care aides made little reference to their interactions with other staff members, including nursing staff. When asked about this omission in the focus groups, the health care aides indicated that although their relationships with nurses were usually genial, the health care aides did not feel supported by nurses. Cruttenden (2006) observed that health care aides looked to nurses for information and support which they did not always receive. In focus groups with nurses and then with nursing assistants (Schirm et al., 2000), the nurses were aware that because of their other duties they did not always respond immediately to the concerns presented by the nursing assistants. They expected the nursing assistants to be more assertive and tenacious when requesting the nurse's attention. The nursing assistants felt undervalued as a result of the nurses' lack of interaction with them. McCloskey et al. (2014) found that health care aides, who had the most contact with residents, did not attend meetings and did not document their findings or engage in dialogue with other care providers. Aubrey

(2013) observed that veteran nursing assistants worked in tightly knit groups and developed their own methods for reducing the time it took to complete caregiving tasks with residents. These methods sometimes contravened organizational policy. For example, talking with residents was discouraged because of the increased time conversation added to the provision of care. These nursing assistants also orientated the new workers, requiring the new workers to develop the same pace of work as the other assistants. It was noted that these cohesive teams of workers were potentially influential within the organization. If managers wanted to implement institutional change, they would need to collaborate with these workers if the change was to be successful (Aubrey et al., 2013).

Hunter and her colleagues studied the relationship between organizational structures and person-centered care (Hunter et al., 2016). This study revealed that organizational factors that supported empowerment of employees also supported person-centered residential dementia care (PCRDC). These factors included the physical and social environment of the resident and supervisory or other organizational supports. Collaboration was the only environmental variable associated with four aspects of person-centered care: personhood, knowing the person, comfort care, and support for relationships. The authors suggested this indicated a need to change organizational processes rather than focusing only on the individual behaviors of staff.

The literature has confirmed the environmental stressors of health care aides, such as workload, time constraints, the effects of having low status and of being undervalued in institutions that adhere to the medical model of care and top-down management practices. The recommended changes in organizational practices for promoting person-centered care as well as the positive attitudes and behaviors of staff included changes that empowered front-line staff

(Hunter et al., 2016). However, this article did not address issues of work load and time constraints, which are work stressors frequently referred to by the participants in this study

The health care aides in this study and “other staff”. Most of the responses of the health care aides in this study revealed personal characteristics of the health care aides that were positive. These included respect for the resident, being caring, empathetic, insightful, and compassionate and having the ability to build and maintain relationships with residents. At the same time, these health care aides frequently referred to “other staff” who did not share their perception of the resident and who were apparently not willing to make the same effort in providing care for the resident as the study participants. This resulted in a “we-they” tone to many of the interviews. Not all of the references to “other staff” were negative. Many of the health care aides in the study commented that when they worked with compatible staff their work was easier and resulted in better resident care. One health care aide spoke of other health care aides going beyond what was required of them to meet the needs of residents. Although the conflict with other staff members has been identified in the literature as one of the work stressors encountered by health care aides (Browne & Braun, 2008; Morgan et al., 2005), I, as the researcher, had no way of verifying the accuracy of the negative comments made by the health care aides about some colleagues. As well, a limitation of the study was that the health care aides who participated in the study were all volunteers and may have represented some of the more competent and confident health care aides working in this health region. Although a larger number of health care aides were involved in the recruitment process, these 24 health care aides were the only ones willing to share their experiences about providing care to residents with dementia with a researcher. For example, only three (12.5%) of the study participants were male. A number of male health care aides took part in the recruitment process but only these three

agreed to be interviewed. It can be assumed that the health care aides who participated in the study were confident of their performance and perhaps even performed better than some of their colleagues. However, since the other limitation of this study is that I, as the researcher, was not able to observe the behaviors of either the study participants or the “other staff”, it cannot be taken for granted that the negative perceptions of the health care of their colleagues were correct. These observations present ideas for further research.

Educational Supports for Health Care Aides

Reference has already been made to health care aides in Canada being poorly trained (Banerjee, 2007; Cummings et al., 2013). Health care aides also work with an expanded but not well defined role and with increasing autonomy (Cummings et al., 2013). The participants in this study were 24 health care aides employed in four long-term care facilities in Winnipeg. Referring to the study of health care aides in all three Prairie Provinces conducted by Estabrooks and her colleagues (Estabrooks et al., 2014), a lower percentage of the health care aides (71%) in this study had graduated from a certified training program compared to health care aides in the other two Prairie Provinces. Nearly a third of the health care aides in the study had a college education inside or outside of Canada and 12.5% had partially completed a nursing training program. Again referring to the sample of health care aides in the study by Estabrooks et al. (2014), the health care aides in Manitoba (57.2%) have taken part in more continuing education programs provided by their employer than those in either Alberta (49.5%) or Saskatchewan (26%). However, the literature provides no measureable outcomes for formal training or in-service education in any of these provinces. The health care aides in this study had less entry-level training than health care aides in the other Prairie Provinces but may have had greater access to employer sponsored educational opportunities. As in all Canadian provinces and

territories, health care aides are unregulated and in Manitoba they are unregistered. None of the technical colleges that provide training for health care aide students in Manitoba have standardized curricula for these students (Estabrooks et al, 2014).

There have been numerous references in the literature about the need for continuing education programs for front-line health care workers to enable them to maintain professional competency and to prepare them to meet the needs of residents with dementia (Castle & Ferguson-Rome, 2015; Cummings et al., 2013; Kennedy, 2005). It has been recommended that: 1) employers provide training in English as a second language (Cummings et al., 2013); 2) extended orientation sessions be provided for training front-line workers in technical skills and to help these workers understand the role of nurses (Schirm et al., 2000); 3) education sessions be developed to increase the ability of health care aides to reduce and manage the agitated behaviors of residents (Cohen-Mansfield et al., 2007; Chrzescijanski et al., 2007; Livingston et al., 2014) and; 4) facility wide education programs be developed for improving the interactions between employees (Anderson et al., 2014). As well, educational programs have been developed to prepare front-line caregivers to work within the model of person-centered care (Passalacqua & Harwood, 2012; Ruckdeschel & Van Haitsma, 2004).

Canadian researchers (Aylward et al., 2003) conducted a literature review of the effectiveness of continuing education programs in long-term care. They identified three quality measures with which to assess the educational programs they reviewed: 1) predisposing factors or the materials used to convey information; 2) enabling factors or the conditions that allowed learners to use their new information; and 3) reinforcing factors that reminded the learners about what they had learned. The authors found no evidence of the effectiveness of the interventions they reviewed but that few of these educational programs included enabling or reinforcing

factors. Reviewers of educational programs for nursing assistants in the United States (Nakhnikian et al., 2002) found there was a lack of supervision to orient new employees or to help them retain the information they learned in certification programs. These reviewers also found that many new employees lacked the necessary proficiency in English to interact with English-speaking residents. These authors encouraged the use of support groups and peer mentors to provide opportunities for brainstorming and sharing ideas. They also identified the need for nursing assistants to learn how to communicate with residents, families and supervisors.

The health care aides in this study agreed that additional learning was important. They expressed limited enthusiasm for the continuing education programs in their facilities. They described these as brief (as short as 30 minutes twice a year) and frequently not providing the information these health care aides needed to provide care for residents with advanced dementia. Some had access to training videos they could watch during their free time. In focus group discussions, a few health care aides expressed a desire to be involved in the development of educational programs, saying, for example, that they would like these programs to be more interactive. Two of the health care aides took part in English as an additional language program offered through their facility. Aside from this example, there was no mention of learning opportunities that met the criteria of Aylward and her colleagues (2003) for enabling and reinforcing learning.

As previously mentioned, health care aides are not a regulated workforce despite the fact they provide most of the direct care to vulnerable residents. It has been recommended that health care aides have standardized provincial or national curricula for achieving certification and a mandatory provincial registry for all employed and student health care aides. It has also been

recommended that an organization be developed in each province to maintain this registry leading to the eventual provincial regulation of health care aides (Estabrooks et al., 2014).

Communication Interactions of Health Care Aides with Residents with Dementia

The health care aides in this study frequently referred to their use of verbal and nonverbal communication strategies with the residents with dementia. They referred to the following: 1) recognizing the need to communicate with residents in recognition of the resident being a respected person; 2) adapting verbal and nonverbal communication to the resident's ability to comprehend what was said and the resident's ability to produce words; 3) adapting their speech through their choice of words, voice tone and nonverbal communication strategies; 4) speaking to both verbal and nonverbal residents, including those with challenging behaviors; 5) developing specific communication strategies for hearing impaired residents; 6) using social gatherings such as mealtimes to promote the residents' communication; 7) refusing to use baby-talk when speaking with residents; and 8) self-monitoring communication to reduce the agitation of residents with challenging behaviors.

Bayles and Tomoeda (2007) described the connection between cognition and communication, with the ability to communicate always being impacted by the progress of the dementing illness. The health care aides in this study persevered in their communication interactions with all residents, including those who were mute, choosing to believe the resident retained some ability to understand the health care aides' verbal and nonverbal interactions. Bonder (1994) described communication as a means of expressing unmet needs. The health care aides in this study frequently expressed their frustration that they could not understand what need the resident was attempting to express, leaving the health care aide in a quandary about how to address this need.

The health care aides often referred to using communication as a means of facilitating care and responding to the emotional needs of the residents. This use of communication by front-line workers with older persons in residential care has been supported by Carpiac-Claver and Levy-Storms (2007). These authors wrote that this communication had two purposes, to promote the completion of tasks and to establish rapport. The communication strategies they recommended were addressing the resident by using the resident's name, inquiring about the resident's wellbeing, asking the resident about their preferences and food choices and giving emotional support and praise (Carpiac-Claver & Levy-Storms, 2007). As the health care aides in this study described the scripts they used to waken residents or to engage with residents during care or feeding activities, the health care aides revealed using the communication strategies described by Carpiac-Claver and Levy Storms.

The health care aides in this study had a positive perception of the resident and therefore refused to speak to the resident in a demeaning or patronizing manner. This is contrary to the findings of speech-language researchers. These researchers observed that when caregivers spoke to older persons their speech often reflected negative stereotypes of aging, was infantilizing and often used to exert control over the residents (Baltes & Zank, 1994; Caporale, 1981; Coupland et al., 1988; Kemper, 1994; La Tourette & Meeks, 2000; Ryan et al., 1989). Since the health care aides had a positive perception of the resident as a respected person, they did not promote the *Communication Predicament of Aging* (Ryan et al., 1986) which results from caregivers responding to older persons according to negative expectations. The outcome of this communication predicament is that caregivers reduce their talk with older persons, ignore what the older person says to them and do not encourage communication with the older person. The older person is not satisfied with this interaction and makes less effort to communicate. Instead,

the health care aides in this study recognized the resident as a respected person with unique communication needs. These health care aides expected the resident to have retained some ability to communicate with them. The health care aides described how they listened to the residents, sometimes sitting beside the resident and holding the resident's hand, looking at the resident in the eye, and attempting to accommodate their response to the resident according to the resident's ability to hear, comprehend and respond. Most of the health care aides described using a combination of verbal and nonverbal communication strategies. They spoke of encouraging communication with residents by using topics related to every day experience, the resident's life story, or even music. These behaviors are consistent with the *Communication Enhancement Model* (Levy-Storms, 2008) as well as with the positive person work set out in Kitwood's model of person-centered care (Kitwood, 1990; 1997).

The most evident inhibitor to the health care aide's ability to communicate effectively with the residents was the difficulty of some to speak English fluently. This became apparent to me, as the researcher, during the course of some of the interviews. The problem of immigrant health care workers lacking the language and cultural experience to interact with care recipients is documented in the literature (Aitken, 1995; Browne & Braun, 2008; Coogle et al., 2007). During the interviews, my experience was that some participants had a limited vocabulary and therefore had to compensate for their lack of linguistic ability by relying on the vocal and nonverbal aspects of their speech such as facial expression and gestures (Caris-Verhallen et al., 1997). These interviews were briefer than those with fluent English speakers due to the participant's having fewer words with which to express their thoughts. These health care aides were able to communicate empathy and engagement but, due to their accented English, their words were not always captured on the audiotaped recording. One can assume that elderly

residents with impaired hearing and comprehension might not have a satisfying communication interaction with these health care aides.

The health care aides in this study almost always revealed a sophisticated understanding of the communication strategies required to meet the needs of the residents with dementia. The health care aides' use of these strategies was not only compatible with the literature about communication and dementia but also with the principles of person-focused care. The origin of this understanding is not clear. When asked, their health care aides sometimes referred to in-service education programs provided they their facilities. However, most agreed they learned how to communicate with the residents through trial and error. They also learned from other health care aides who, upon discovering an approach that worked with a resident, often shared their experience with other the health care aides.

Conclusions and Recommendations

The 24 health care aides who participated in this study were unanimous in their understanding that the resident with dementia was a respected person with whom they were in a relationship and a care recipient who also demonstrated challenging behaviors. The health care aides' resulting attitudes, behaviors, and communication interactions with these residents, as reported by them during the interviews, were compatible with both the principles of person-centered care and the literature about communication and dementia. These findings indicate the need for both the health care system generally as well as individual long-term care facilities to find ways to promote these positive attitudes and behaviors by all health care aides employed to work with residents with dementia. The following recommendations are made with a view of meeting this challenge within the resources currently available within the long-term care health system. They include recommendations about supporting and empowering health care aides

within the organizational structures in which they work. Other recommendations refer to educational supports that would better prepare health care aides to meet the complex needs of the residents currently residing in long-term care facilities. Finally, there are recommendations about future studies and knowledge translation.

Supporting health care aides within the organizational structure. Staff shortages was one of the major inhibitors to the health care aides being able to act on their interpretation of the resident as a respected person. However the current environment of fiscal restraint for all health care spending makes the hiring of additional health care aides unlikely. Equally unlikely is the hiring of more nurses to provide supportive supervision for the health care aides currently in the system. The challenge becomes how to use existing resources to support health care aides so they function more efficiently and have more time to interact with residents. There are three recommendations regarding how to support health care aides within the organization structure. They are: 1) the development of a clear description of the role and scope of practice of health care aides; 2) a modification of the workload of health care aides; and 3) an improved workplace culture.

One concern identified in the literature was the lack of a clear definition of the role and scope of practice of health care aides (Estabrooks et al., 2014). It is recommended that managers of health care facilities develop such a description of the responsibilities of health care aides, excluding tasks that could be done by lesser trained staff or even volunteers. These tasks include sorting and storing supplies, transporting residents and even serving meals. Managers from a number of facilities, such as the facilities in a health care region, could develop such a delineation of tasks that would result in a consistency of the interpretation of the health care

aides' roles between facilities. Since some health care aides work part-time in more than one facility, this would result in a consistency of the expectation of health care aides across facilities.

As already mentioned, it has been observed that health care aides are asked to perform a number of tasks that are not related to direct resident care. As well, they are interrupted up to every three minutes while performing these tasks (Mallidou et al., 2013). To address this issue, nursing managers within each facility could study the work flow of health care aides to ensure that health care aides are able to use their time effectively with a reduced number of interruptions during their interactions with residents. Again, these observations could be shared between facilities.

Another way of modifying the workload of health care aides is the greater utilization of continuity of care. When health care aides work with the same residents over time, they are more familiar with the caregiving activities associated with that resident and can presumably perform the care more efficiently while having the opportunity to develop a relationship with the resident. From my personal experience as an occupational therapist in long-term care, I have observed a possible negative effect of this policy. At times, health care aides have asked to care for a different resident, either because of the challenges presented by the resident or because of the health care aide's desire for contact with other residents. Therefore, supporting the health care aide within the organizational system should reflect a recognition of the needs and preferences of health care aides, when possible, to prevent burnout and possible negative interactions with residents.

The findings of the study also indicated the need to change the work culture of the long-term care facility. Many of the health care aides in this study described conflict with other staff members and lack of support from nurses. They described the stress they experienced as a result

of interactions with other health care aides who did not share the same perception of the resident. Another observation revealed in the interviews with the health care aides in this study was the degree to which they worked in isolation from other staff including nurses and allied health professionals. One health care aide said that interacting with nurses was unnecessary because the health care aide already knew his/her job. Other health care aides spoke of not receiving assistance from nurses when this was asked for or nurses not passing on the observations of health care aides about residents to other staff, including physicians. However, they also spoke of how efficiently they could work when paired with a congenial and cooperative co-worker.

There are three proposed recommendations aimed at changing the work-place culture in which all long-term care staff members function. The first is for nurses to develop strategies to build trusting yet professional relationships with the health care aides and become more interactive with them. This may require nurses to develop new skills in the supervision of subordinate staff. As observed by Jung (1991), many registered nurses do not have the necessary skills to supervise subordinate staff. However, much that is written about the supervision of health care aides has to do with delegating tasks specific to the health care aide's role (College of Registered Nurses of British Columbia, 2013; Jung, 1991) instead of interacting with health care aides to provide supervisory support. In addressing how to improve work-place culture, it is suggested that nurses be trained to develop professional interpersonal relationships with subordinates, including skills in conflict resolution. Since long-term care facilities respond to fiscal restraints by hiring a higher ratio of unregulated staff to registered nurses, the need for such training becomes more apparent. The development of training programs to provide registered nurses with supervisory skills need to supervise these unregulated staff members could be developed by either faculties of nursing or nursing regulatory bodies.

The second focus for improving work-place culture is the promotion of positive relationships between all levels of staff. Anderson (2014) conducted a study of the positive and negative interactions between all levels of care staff in nursing homes in England. She observed that positive interactions between staff benefited all levels of staff and lead to improved patient care. She referred to positive behaviors such as saying “thank-you”, not being critical of others and doing one’s share of the work. She found the results of using positive behaviors were an increase in the connectedness between staff members, a greater exchange of information and a greater involvement of all staff members in decisions making. The use of positive interaction strategies between staff also corresponds to the principles of person-centered care (Kitwood, 1997). Although designed to improve the relationships between caregivers and care recipients, the principles of recognizing the value of other persons and acting in a respectful and supportive manner toward them could be recognized as foundational in the development of a positive work culture.

The third strategy for improving work culture is the acknowledgment of the positive contributions of all staff, but particularly health care aides. The positive attitudes and behaviors described by the health care aides in this study could be promoted as patterns of behavior to be adopted by other staff. These health care aides could be recognized as role models instead of being left open to the criticism of staff members who do demonstrate these attitudes and behaviors. Finally, the health care aides in this study commented on how much less stressful their work was when they could work with a congenial partner. Nursing managers could acknowledge that some staff members work well together and attempt to develop work schedules that allow for such partnering.

Educational programs, registration and regulation. The findings of this study showed that the health care aides who were interviewed appeared to have competencies in person-centered care, addressing the emotional needs of residents with dementia, the development of meaningful relationships, the implementation of communication strategies and the management of challenging behaviors. However, it cannot be assumed that all health care aides practicing with this resident population have the same competencies. At the same time, the health care aides in this study demonstrated a general lack of formal knowledge about dementia. As well, many reported that most of what they knew about providing care for residents with dementia and interacting with these residents was the result of their work experience and learning from other health care aides. This indicates the need for health care aides to receive more information about providing care to residents with dementia from the technical colleges that prepare the health care aides for certification.

In a study about the health care aide workforce in Alberta, Cummings and her colleagues (2013) made a number of recommendations about the formal training of health care aides. First, they stated the need for a clear definition of the current roles of health care aides to reflect their increased responsibilities and greater autonomy. Then they proposed that the entrance qualifications, English proficiency requirements and curricula for training programs for health care aides should be standardized. The work of Cummings and her colleagues (2013) supports the need for training colleges to develop curricula that represent the current role of health care aides, especially those working with residents with cognitive impairments.

For health care aides working in long-term care in Manitoba, over 60% of the residents have moderate to severe dementia. This strongly indicates the need for curricula with an emphasis on topics directly relevant to preparing health care aides for meeting the needs of these

residents. These topics include the concepts of person-centered care and communication and dementia. In addition, some of the health care aides in this study identified the need for more training in English as an additional language.

The expansion of training programs to include material about dementia care would mean these programs would take longer to complete. One unfortunate result would be an increase in the costs of these programs resulting in financial hardship for some perspective students. This suggests the need for the provision of financial assistance for student health care aides. Both of these moves, expanding the curricula and providing financial assistance to students, could ultimately result in an improvement in the care provided to all residents of long-term care facilities.

Continuing education programs sponsored by facilities will continue to be necessary to ensure that health care aides maintain their competencies and acquire new information that is relevant to their practice. The health care aides in this study voiced three concerns about continuing education programs in their facilities. First, they requested having input when these programs are developed so that the programs would meet the health care aides' specific learning needs and styles of learning. Secondly, they wanted to learn more about how to provide care to the residents with severe cognitive impairment. Finally, they expressed a desire that continuing education programs be more interactive, with the health care aides having more contact with the instructor. This suggests the use of alternative teaching methods. For example, instruction could be modularized and delivered in short but more frequent sessions than the annual or bi-annual events described by the health care aides in this study. Locating teaching sessions on the nursing unit could facilitate the enabling and reinforcing of learning. The health care aides would be able to ask questions and have direct feedback from instructors. The instructors could be nursing or

allied health professionals who are already employees of the institution, thus saving the cost of hiring special instructors. This practice would also serve to increase the interactions of health care aides with other facility personnel. Finally, employer sponsored language training for staff with English as a second or additional language (Cummings et al., 2013; Estabrooks, 2014) could contribute greatly to these health care aides being able to interact with residents and families. Long-term care managers could recognize the maintenance of a well-informed front-line staff as an important contributor the delivery of high quality care to residents and a major asset to their organization.

Registration and regulation of health care aides. Estabrooks et al (2014) write of the need for mandatory registration of health care aides and the development of provincial regulatory bodies. The health care aides in this study represented a range of formal instruction for becoming health care aides, with one health care aide having no formal training. There was no record of their employment or work performance other than records maintained by the facility in which they worked. Health care planners in Manitoba have no single source of information about the numbers or characteristics of these workers or how to support this workforce. Estabrooks and her colleagues found that six provinces already have registries of employed and student health care aides. The data within these registries include demographic and contact information, workforce employment, attrition and mobility information and educational background and certification. According to Estabrook (Estabrook et al., 2014), information from these registries can identify inconsistencies in training and workplace characteristics that precipitate burnout with implications for quality of care, staff health, and staff retention.

Although there are recognized benefits to the creation mandatory registries, in Manitoba there is no existing mechanism for developing such a registry. Advocacy for creating a registry

of health care aides could come from the regional health authorities or an organization such as the Continuing and Long Term Care Association of Manitoba. However, current fiscal restraints create an unfavorable climate for the development of a new program that would require both human and financial resources. This does not mean the idea of a registry should be abandoned, but to understand that its creation might need to be left to a future time.

There is no province in Canada where health care aides are regulated (Bangerjee, 2007; Cummings et al., 2013; Estabrooks et al., 2013) and therefore there is no structure by which health care aides are held accountable to the public. Regulation of health care aides would not only provide this accountability but would also require that the role and scope of practice of health care aides be clearly defined (Cummings et al., 2013). This in turn would reduce the ambiguity and stress experienced by health care aides that is associated with unclear role expectations. Regulation of health care aides would also support the maintenance of professional competence of health care aides through required continuing competency activities.

However, there are negative aspects to the creation of regulatory bodies for health care aides. Foremost is the cost of the creation and maintenance of such a body. Unless this body was subsidized, the full cost of creating and maintaining it would fall upon the health care aides themselves. Health care aides are the lowest paid of the health care work force and the cost of registration might be beyond their ability to pay. A possible result could be health care aides leaving the profession. As well, the additional costs associated with regulation could trigger health care aides demanding higher salaries.

Aside from the costs associated with regulation, being certified as a member of a regulated profession might change how health care aides perceive themselves in their role with residents. They might exhibit “professional behaviors” that include creating more emotional

distance between themselves and residents. Recalling the caring and affectionate behaviors of the health care aides towards residents that were revealed in this study, this would certainly be an unhappy byproduct of regulation.

Future studies. One of the limitations of this study was that the participants were self-selected. As well, the sample consisted mainly of female participants. Another element of homogeneity was that all the participants liked their work and were confident in their abilities to meet the expectation of their role. They all shared the same perceptions of the residents with dementia and revealed the same attitudes and behaviors related to the provision of this care. There was no opportunity to interview health care aides who did not share these attitudes or perceptions. One purpose of future research would be to test the findings of this study with other populations of health care aides in order to add new perspectives about the interactions of health care aides with residents with dementia.

One way to address the issue of the high unanimity of the responses of the health care aides would be to replicate the study in a different health region, preferably in a rural area. Another approach might be to conduct the study in a psychiatric setting which has residents with dementia. These studies might draw out participants with different cultural values and experiences and who might therefore respond differently to the study questions.

Another way of attempting to engage a less homogenous group of health care aides would be to conduct a paper survey with guaranteed anonymity for the respondents. The questions could be drawn from this study. For instance, questionnaires could be delivered to a facility by the researcher who would be available to explain the purpose and confidentiality of the study to the health care aides and who could also collect the completed questionnaires.

Finally, although I was not able to observe the health care aides interacting with the residents and co-workers, a study could be conducted with unit managers of special care units in long-term care facilities within and outside of Winnipeg. These are the supervisors who have daily contact with health care aides and have the opportunity to observe their behaviors. This study could involve interviewing managers and again using questions generated from this study. The purpose would be to test the findings of this study and to generate new information from the managers.

Knowledge Translation. Knowledge translation or turning knowledge into action (Graham et al., 2006) will be a critical process in the implementation of the recommendations emanating from this study. I will attempt to use the processes of dissemination and diffusion of information about the findings of this study to achieve their utilization and implementation by stakeholders in long-term care in Manitoba (Estabrooks et al., 2006; Graham, et al., 2006).

The findings from this study I want to communicate to stakeholders are: a) a description of the attitudes and behaviors of the health care aides in this study that resulted from their perception of the resident as a respected person; b) a description of the interactions and caregiving practices of these health care aides which in turn supported the principles of person-centered care and the theories of communication and dementia; c) an explanation of why these perceptions and practices should be promoted to enhance the quality-of-life and health of residents with dementia in long-term care; d) a description of the major inhibitors to these perceptions and behaviors such as was work related stressors; e) the limited training and education about dementia that the health care aides had received in their formal training.

In my efforts to disseminate the information and recommendations coming from this study, I will refer to the *Knowledge-to-action Process* proposed by Graham, Tetroe, and the KT

Theories Research Group (2007). This model shows that to achieve the transition of knowledge to practice, one must select and adapt the message to the local context and assess barriers to knowledge use. Recognizing that the transfer of the knowledge from this study into action will depend on the support of a number of stakeholders, I will modify presentations according to the audience. I will not only disseminate the findings but attempt to stimulate conversations with and between these groups. Such interactions will hopefully lead to the recognition of the importance of the findings of this study and their implementation to both the welfare of residents of long-term care facilities' and health care aides. These groups of stakeholders include the Winnipeg Regional Health Authority, chief executive officers and managers of individual facilities as well as organizations including the Continuing and Long Term Care Association of Manitoba and the Manitoba Alzheimer Association. I will make presentations at the annual conferences of provincial organizations such as the Manitoba Alzheimer's Society, Palliative Manitoba and the University of Manitoba Centre on Aging. I will also apply to make presentations nationally to organizations such as the Canadian Alzheimer's Society and the Canadian Association of Palliative Care. As well, I will attempt to meet with senior representatives of the Health Care Aide Program at Red River College as well as at Robertson College and Herzing College. The purpose of these meetings would be to stimulate discussions about incorporating information about person-centered care and communication and dementia into their curricula. Finally, I will submit articles for publication to journals of health management as well as journals of clinical practice.

Knowledge translation and study participants. All of the participants in this study requested a copy of a report of the study findings. I will develop a report that is designed specifically for the participants with a covering letter. The covering letter will remind the

participant of his/her participation in the study and thank him/her for their participation. I will include the following in the report of the findings: a) a brief description the study sample of the participants; b) the name of the methodology of the study; c) the visual model of the theory with the name of the theory; c) an explanation of the theory, “The resident being perceived as a respected person”; d) a list of the facilitators of this interpretation of the resident; e) a list of the inhibitors of this perception of the resident; f) the consequences of this interpretation of the resident; g) a brief explanation of the nine themes of person hood use in the study.

Meetings with the managers of the study sites. I have agreed to make a presentation about the study to the managers of each of the four facilities that participated in the study. I will develop a presentation that includes the methods of the study, a description of the sample, an explanation of the theory, and the recommendations resulting from the findings. I will be anxious to answer questions that come from these managers. Aside from addressing any concerns they might have about the study, their questions will provide me with insight into how to describe and explain the study to other groups and in publications.

I will ask the nursing managers of the four facilities to permit me to make a presentation about the study to health care aides in each of their facilities. This meeting would presumably be for any health care aide in the facility working with residents with dementia including health care aides who had participated in the study. Such a meeting would allow me to have direct contact with health care aides and to address their questions about the findings of the study. It might also serve as an opportunity to affirm to the health care aides the significance of their role with residents with dementia.

Limitations of the Study

There are two limitations to this study. The first is that the sample was a convenience sample of health care aides who volunteered to participate in the study. There is no evidence of how representative they are of the total population of health care aides employed provincially or nationally. As well, there were only nine participants in the four focus groups. Therefore, the information generated during these groups represented less than half of the total number of participants.

Secondly, I did not observe the interactions of the health care aides with residents with dementia. There I was therefore unable to verify if the health care aides interacted with the resident in the way they described and if this behavior was consistent. I was also unable to observe the behaviors of the “other staff” that were described by the health care aides participating in this study.

The health care aides who agreed to participate in this study stated they felt positively about their work with residents with dementia. They provided socially acceptable responses which raise the question if they were telling me what they expected I wanted to hear. However, if they did attempt to skew their answers to satisfy my expectations, they all did this with similar responses. The analysis of the data of this study provided no explanation for this phenomenon nor is there an explanation of the origins of the positive and caring attitudes and the insight of the health care aides who agreed to participate in this study. Future studies could be undertaken to address the questions raised by these gaps in the knowledge gained from this study.

Summary

Twenty-four health care aides from four long-term care facilities in Winnipeg perceived the residents with dementia whom they cared for as continuing to be respected persons with

whom they were in a relationship and as care recipients who were potentially threatening and abusive. The primary facilitators of these perceptions were the personal characteristics of the health care aides while the primary inhibitors were work-related stressors including heavy workloads and limited supervision as well as limited educational preparation. There is little explanation for the source of the beliefs, values, and attitudes of the health care aides which led to this perception of the resident. However, their interactions with the residents were consistent with the principles of person-centered care and the theoretical concepts related to communication and dementia.

References

- Adams, T., & Gardiner, P. (2005). Communication and interaction within dementia care triads. *Dementia*, 4(2) 185-205. Retrieved from <http://dem.sagepub.com>
- Aitken, M. (1995). The human cost of performing the nursing assistant's role. *Canadian Nursing Home*, 6(2), 6-13.
- Albrecht, T.L., Johnson, G.M., & Walther, J.B. (1993). Understanding communication processes in focus groups. In D.L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 51-64). Newbury Park, CA: Sage Publications, Inc.
- Alzheimer Society of Canada (2010). Rising tide: The impact of dementia on Canadian society. Retrieved from http://www.alzheimer.ca/docs/RisingTide/Rising%20Tide_Full%20Report_Eng_FINAL_Secured%20version.pdf
- Alzheimer Society of Canada (2015). *Alzheimer disease: The progression of Alzheimer disease*. Retrieved from <http://www.alzheimer.ca/english/disease/progression-intor.htm>
- Anderson, R.A., Toles, M.P., Corazzini, K., McDaniel, R.R., & Colon-Emeric, C. (2014). Local interaction strategies and capacity for better care in nursing homes: A multiple case study. *BMC Health Sciences Research* 2014, 14:244.
- Anells, M. (1997). Grounded theory method, part I: Within the five moments of qualitative research. *Nursing Inquiry*, 4, 120-129.
- Atchely, R.C. (1989). A continuity theory of normal aging. *Gerontologist* 29(2), 183-190.
- Aubry, F, Etheridge, F., & Couturier, Y. (2013). Facilitating change among nursing assistants in long term care. *Online Journal of Issues in Nursing*, 18(1).

<http://web.a.ebsohost.com.proxy2.lib.umanitoba.ca/ehost/delivery?sid=cd875f4d-ca84-4c...>

Association of Canadian Community Colleges (2012). *Canadian educational standards for personal care providers: Environmental scan*. Retrieved from <https://www.cikkegesunstuytes.ca/wp-content/uploads/2014/05/Canadian-Standards-Environmental;Scan.pdf>

Aylward, S., Stolee, P., Keat, N., & Johncox, V. (2003). Effectiveness of continuing education in long-term care: A literature review. *The Gerontologist*, 43(2), 259-275.

Azermai, M. (2014). Dealing with behavioral and psychological symptoms of dementia: A general overview. *Dovepress*, 2015(8), 181-185

Baltes, M. M., Neumann, E.M., & Zank, S. (1994). Maintenance and rehabilitation of independence in old age: An intervention programs for staff. *Psychology and Aging*, 9, 179-188.

Banerjee, N. V. (1974). *Kant's philosophy of the self*. New Delhi, Arnold-Heinemann Publishers.

Banerjee, A. (2007). *An overview of long-term care in Canada and selected provinces and territories*. Retrieved from http://www.womenandhealthcarerfrom.ca/publications/banerjee_overview.TC.pdf

Banerjee, A., Daly, T., Armstrong, P., Szebehely, M., Armstrong, H., & Lafrance, S. (2012). Structural violence in long-term, residential care for older people: Comparing Canada and Scandinavia. *Social Science and Medicine* 74 (2012), 390-398.

Bayles, K. & Tomoeda, C. (2007). *Cognitive-communication disorders of dementia*. San Diego: Plural Publishing Inc.

- Bergener, S. C. (1996). *Communicating with residents with Alzheimer's dementia: A study of nurse/resident interactive behavior*. UMI Dissertation Services.
- Berghmans, R. L. (1998). Advance directives for non-therapeutic dementia research: Some ethical and policy considerations. *Journal of Medical Ethics* 24: 32-37.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. New Jersey: Prentice-Hall, Inc.
- Bogdan, R. & Taylor, S.J. (1989). Relationships with severely disabled people: The social construction of humanness. *Social Problems*, 36(2), 135-148.
- Bonder, B. R. (1994). Psychotherapy for individuals with Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 8(3), 75-81.
- Buber, M. (1996). *I and Thou* (W. Kaufmann). New York: Simon & Schuster.
- Buchanan, A.E., & Brock, D.W. (1990). *Deciding for others: The ethics of surrogate decision making*. New York: Cambridge University Press.
- Burns, N. (1989). Standards for qualitative research. *Nursing Science Quarterly*, 2(44), 44-52.
- Browne, C.V. & Braun, K.L. (2008). Immigration and the direct long-term care workforce: Implications for education and policy. *Gerontology & Geriatrics Education*, 29(2), 172-188.
- Bryan, K., Maxim, J. (1996) *Communication disability and the psychiatry of old age*. United Kingdom: Atheneum Press Ltd.
- Byrne, K., & Orange, J.B. (2005). Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICF framework. *Advances in Speech-Language Pathology*, 7(4), 187-202.

Canada Health Act 1984 c.6, s.1. Retrieved from <http://laws.justice.gc.ca/en/charter/index.htm>

Canadian Association of Occupational Therapists (CAOT). (1997). *Enabling occupation: An occupational therapy perspective*. Ottawa: CAOT Publications ACE.

Canadian Association of Occupational Therapists (CAOT). (1998). *Living at home with Alzheimer's disease and related dementias*. Ottawa: CAOT Publications ACE.

Canadian Health Care Aide Schools (2009). *Health care aide schools & colleges*. Retrieved from <http://www.trade-schools.ca/programss/health-care-aide.asp>

Canadian Institute for Health Information (2013). *When a nursing home is home: How do Canadian nursing homes measure up on quality?* Ottawa, ON: Author.

Canadian Institutes of Health Research (2016). *Knowledge translation at CIHR*. Retrieved from <http://www.cihr-irsc.gc.ca/e/29418.html>

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences & Humanities (2014). *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa, ON: Government of Canada

Caporaël, L. (1981). The paralinguistic of caregiving: Baby talk to the institutionalized aged. *Journal of Personality and Social Psychology*, 40, 876-884.

Caporaël, L.R., Lukaszewski, M.P., & Culbertson, G.H. (1983). Secondary baby talk: Judgments by institutionalized elderly and their caregivers. *Journal of Personality and Social Psychology*, 44(4), 746-754.

Caris-Verhallen, W.C.M., Kerkstra, A., & Bensing, J.M. (1997). The role of communication in nursing care for elderly people: A review of the literature. *Journal of Advanced Nursing*, 25, 915-933.

- Carpac-Claver, M.L., & Levy-Storms, L. (2007). In a manner of speaking: Communication between nurse aides and older adults in long-term care settings. *Health Communications*, 22(1), 59-67.
- Castle, N.G., & Ferguson-Rome, J.C. (2015). Influence of nurse aide absenteeism on nursing home quality. *The Gerontologist*, 55(4), 605-615.
- Chappell, N., & Novak, M. (1992). The role for support in alleviating stress among nursing assistants. *The Gerontologist*, 32(3), 351-459.
- Chenitz, W.C. (1986). Getting started: The research proposal for a grounded theory study. In W.C. Chentiz & J.M. Swanson (Eds.), *From practice to grounded theory: Qualitative research in nursing* (pp. 39-47). Menlo Park, CA: Addison-Wesley Publishing Company.
- Cherryholmes, C.H. (1992). Notes on pragmatism and scientific realism. *Educational Researcher*, 13-17.
- Cheston, R. (1996). Stories and metaphors: Talking about the past in a psychotherapy group for people with dementia, *Aging and Society*, 16, 579-602.
- Cheung, P.Y. & Yam, B.M.C. (2004). Patient autonomy in physical restraint. *International Journal of Older People Nursing/Journal of Clinical Nursing*, 14(3a), 34-40
- Choi, J., & Johantgen, M. (2012). The importance of supervision in retention of CNAs. *Research in Nursing and Health*, 35, 187-199.
- Christiansen, C. H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence and the creation of meaning. *The American Journal of Occupational Therapy*, 53(6), 547-558.
- Chrzescijanski, D., Moyle, W., & Creedy, D. (2007). Reducing dementia-related aggression through staff education intervention. *Dementia*, 6(2), 271-286.

- Cohen-Mansfield, J, Libin, A., & Marx, M.(2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *Journal of Gerontology: MEDICAL SCIENCES*, 62A(8),908-916.
- College of Registered Nurses of British Columbia (2013). *Assigning and delegating to unregulated health care providers*. Retrieved from:
<https://www.crnbc.ca/Standards/PracticeStandards/Pages/delegating.aspx>
- College of Nurses of Ontario (2009). *Practice standard: Restraints*. Toronto: Author
- College of Registered Nurses of Manitoba, (2011). *Professional boundaries for therapeutic relationships*. Retrieved from
https://www.crnmb.ca/uploads/document/document_file_99.pdf?t=1438267436
- Coogle, C.L., Parham, I.A., & Young, K.A.(2007). Job satisfaction and career commitment among nursing assistants providing Alzheimer's care. *American Journal of Alzheimer's Disorders and Other Dementias*, 22, 251-260.
- Cooney, A. (2010). Choosing between Glaser and Strauss: an example. *Nursing Researcher*, 17(4), 18-28.
- Coupland, N., Coupland, J., Giles, H., & Henwood, K. (1988). Accommodating the elderly: Invoking and extending a theory. *Language and Society*, 17, 1-41.
- Cranley, L.A., Norton, P.G., Cummings, G., Barnard, D., Batra-Garga, N., & Estabrooks, C.A. (2012). Identifying resident care areas for a quality improvement intervention on long-term carer: A collaborative approach. *BMC Geriatrics*, 12(59), 1-5.
- Creswell, J.W. (2013). *Qualitative inquiry and research design: Choosing among the five approaches*. Los Angeles: SAGE Publications Inc.

- Crisis Prevention Institute (2016). *Non-violent crisis intervention: Change culture, behavior, and relationships*. Retrieved from www.crisisprevention.com/CPI/media/Media/specialties/nci/Program-Benefit.pdf.
- Cruttenden, K.E. (2006). Long-term care planning study: Strengths and leaning needs of nursing staff. *Canadian Journal on Aging*, 25(4), 347-361.
- Cummings, G. G., Spiwek, T., Hewko, S., Cooper, S., Lynch, S., & Huynh, H. (2013). *Shining a light on the unregulated healthcare aide workforce*. Edmonton, AB: Faculty of Nursing, University of Alberta. Retrieved from <http://www.trec.ualberta.ca/en/~media/trec/documents/reports/finalalbertahealthreportshiningalight12.pdf>
- Cutcliffe, J.R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.
- Dennett, D. (1976). *Conditions of personhood: The identities of persons*. A. O. Rorty. Berkeley, University of California Press.
- Denzin, N.K., & Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks: SAGE Publications.
- Depoy, E., & Gitlin, L.N. (1998). *Introduction to research: Understanding and applying multiple strategies*. USA: Mosby, Inc.
- Egan, M. & DeLaat, M. (1997). The implicit spirituality of occupational therapy practice. *Canadian Journal of Occupational Therapy* 63(3), 181-85.

- Egan, M.Y., Munroe, S., Hubert, C., Rossiter, R., Gauthier, A., Eisner, M., ... Rodrigue, C. (2007). Caring for residents with dementia and impact of life history knowledge. *Journal of Gerontological Nursing, 33*(2), 24-30.
- Elder, G., Jr. (1977). Family history and the life course. *Journal of Family History 2*(4), 279-304.
- Elder, G., Jr. (1998). The life course as developmental theory. *Child Development 69*(1): 1-12.
- Elder, G., Jr., Shanahan, M.J., & Colerick Clipp, E. (1994). When war comes to men's lives: Life-course patterns in family, work, and health. *Psychology and Aging 9*(1), 5-16.
- Ericsson, I., Kjellstrom, S., & Hellstrom, I. (2011). Creating relationships with persons with moderate to severe dementia. *Dementia, 12*(1), 63-79.
- Estabrooks, C.A., Thompson, D.S., Jacque, J., Lovely, J. E., & Hofmeyer, A. (2006). A guide to knowledge translation. *The Journal of Canadian Education in the Health Professions, 26*, 25-36.
- Estabrooks, C.A., Squires, J.E., Carleton, H.L., Cummings, G.G., & Norton, P. G. (2014). Who is looking after Mom and Dad? Unregulated workers in Canadian long-term care homes. *Canadian Journal on Aging, 1-13*. <https://dx.doi.org/10.1017/S0714980814000506>
- Glaser, B.G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: The Sociology Press.
- Goldsmith, M. (1998). *Hearing the voice of people with dementia: Opportunities and obstacles*. London: Jessica Kingsley Publishers.
- Goodridge, D.M., Johnston, P., & Thomson, M. (1996). Conflict and aggression as stressors in the work environment of nursing assistants: Implications for institutional elder abuse. *Journal of Elder Abuse and Neglect, 8* (1), 49-67.

- Graham, I.D., Logan, J., Harrison, M. B., Straus. S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions*, 26, 13-24.
- Guba, E.G. & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In Denzin, N.K. & Lincoln, Y. S. (Eds.), *Handbook of Qualitative Research* (pp. 106-117). Thousand Oaks: SAGE Publications.
- Guba, E.G. & Lincoln, Y.S. (2005). Paradigmatic controversies, contradictions, and emergent confluences. In Denzin, N.K. & Lincoln, Y. S. (Eds.), *The SAGE Handbook of qualitative research*, 3rd Ed. (pp. 191-215)/ Thousand Oaks: SAGE Publications.
- Guralnik, D.B., & Friend, J.H. (1966). *Webster's new world dictionary of the American language: College edition*. Cleveland: The World Publishing Company
- Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: Incorporating reflexivity and relationality. *Qualitative Health Research*, 11(2), 257-272.
- Hareven, T. K. (1982). The life course and aging in historical perspective. *Aging and Life Course Transitions: An Interdisciplinary Perspective*. T. K. Hareven, Adams, K.J., New York: The Guilford Press.
- Harrison, C. (1993). Personhood, dementia and the integrity of a life. *Canadian Journal on Aging* 12(4).
- Herzing College (2016). *Earn your health care aide diploma in just 20 weeks*. Retrieved from www.jerzomg.ca/winnipeg/landing/healthcare-aide/?midide/?mid
- Hughes, J. C. (2001). Views of the person with dementia. *Journal of Medical Ethics* 27, 86-91.
- Hughes, J. & Common, J.(2015). Ethical issues in caring for patients with dementia. *Nursing Standard*, 29(49), 42-47.

- Human Resources Skills Development Canada (HRSDC) (2009). *Essential skills for health care aides*. Retrieved from <http://www.oic-ci.gc.ca/eng/search-recherche.html>
- Hunter, P.V., Hadjistavropoulos, T., Thorpe, L., Lix, L.N., & Malloy, D.C. (2016). The influence of individual and organizational factors on person-centred dementia care. *Aging and Mental Health, 20*(7), 700-708. <http://dx.doi.org/10.1080/13607863.2015.1056771>
- Janzen, S., Zecevic, A.A., Kloseck, M. & Orange, J.B. (2013). Managing agitation using nonpharmacological interventions for seniors with dementia. *American Journal of Alzheimer's Disease & Other Dementias, 28*(5), 524-532.
- Jenkins, J. (1996). *Social identity*. London: Routledge.
- Jeon, Y. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences, 18*, 249-256.
- Jutkowitz, E., Brasure, M., Fuchs, E., Shippee, T., Kane, R.A., Fink, H. A., Butler, M....Kane, R.L. (2016). Care-delivery interventions to manage agitation and aggression in dementia nursing home and assisted living residents: A systematic review and meta-analysis. *Journal of American Geriatrics, 64*, 477-488.
- Jung, F.D. (1991). Teaching registered nurses how to supervise nursing assistants. *JONA, 21*(4), 32-36.
- Kemper, S. (1994). Elderspeak: Speech accommodations to older adults. *Aging and Cognition, 1*, 17-28.
- Kemper, S. & Harden, T. (1999). Experimentally disentangling what's beneficial about elderspeak from what's not. *Psychology and Aging, 14*, 656-670.
- Kennedy, B.R. (2005). Stress and burnout of nursing staff working with geriatric clients in long-term care. *Journal of Nursing Scholarship, 34*(4), 381-382.

- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Aging and Society*, 10,177-196.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham/Philadelphia: Open Universities Press.
- Kitwood, T. (1998). Toward a theory of dementia care: Ethics and interaction. *The Journal of Clinical Ethics* 9(1), 23 -34.
- Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Aging and Society* 12: 269-287.
- Kolanowski, A. M., & Whall, A.L. (1996). Life-span perspective of personality in dementia. *Image: Journal of Nursing Scholarship* 28(4): 315-320.
- Krefting, L. (1990). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 214-222.
- Krueger, R.A., & Casey, M.A. (2009). *Focus groups: A practical guide for applied research*. Los Angeles: Sage.
- La Tourette, T., & Meeks, S. (2000). Perceptions of patronizing speech by older women in nursing homes and in the community: Impact of cognitive ability and place of resident. *Journal of Language and Social Psychology*, 29(4), 463-473.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9-23.
- Leonard, R., Tinetti, M.E., Allore, H.G., & Drickamer, M.A. (2006). Potentially modifiable resident characteristics that are associated with physical or verbal aggression among

- nursing home resident with dementia. *Archives of Internal Medicine*, 166(12), 1295-301.
<https://dx.doi.org/10.1001/archinte.166.12.1295>.
- Levy-Storms, L. (2008). Therapeutic communication training in long-term care institutions: Recommendations for future research. *Patient Education and Counseling*, 73, 8-21.
- Livingston, G., Kelly, L., Lewis-Homes, E., Baio, G., Morris, S., Patel, N., Omar, R.Z...Copper, C (2014). Non-pharmacological interventions for agitation in dementia: Systematic review of randomized controlled trials. *The British Journal of Psychiatry*, 205; 436-442.
<https://doi.org/10.1192/bjp.bp.113.141119>
- Magia, C., Cohen, C.I., & Gomberg, D. (2002). Impact of training dementia caregivers in sensitivity to nonverbal emotion signals. *International Psychogeriatrics*, 14(1), 25-38.
- Mallidou, A.A., Cummings, G.G., Schalm, C., & Estabrooks, C.A. (2013). Health care aide's use of time in a residential long-term unit: A time and motion study. *International Journal of Nursing Studies* 50, 1229-1239.
- Manitoba Centre for Health Policy (2004). *Using administrative data to develop indicators of quality care in personal care homes*. Retrieved from
<http://www.umanitoba.ca/faculties/medicine/units/mchp/projects/pchqu.html>
- Manitoba Alzheimer Society (2002). *A strategy for Alzheimer disease and related dementias in Manitoba*. Winnipeg: Government of Manitoba.
- Martin, D.G. (2000). *Counseling and therapy skills*. Prospect Heights, Illinois: Waveland Press Inc.
- McCallin, A.M. (2003). Designing a grounded theory study: Some practicalities. *Nursing in Critical Care*, 8(5), 203-208.

- McCallion, P., Toseland, R.W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *The Gerontologist*, 39(5), 546-558.
- McCloskey, R., Donovan, C., Stewart, C., & Donovan, A. (2015). How registered nurses, licensed practical nurses, and resident aides spend time in nursing homes: An observational study. *International Journal of Nursing Studies* 52, 1475-1483.
- McCurdy, D. B. (1998). Personhood, spirituality, and hope in the care of human beings with dementia. *The Journal of Clinical Ethics* 9(1), 81-91.
- McGilton, K.S. (2004). Relating well to persons with dementia: A variable influencing staffing and quality of care outcomes. *Alzheimer's Care Quarterly*, 5(1), 71-80.
- McGilton, K.S., & Boscart, V.M. (2006). Close care provider-resident relationships in long-term care environments. *Journal of Clinical Nursing*, 16, 2149-2157.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5, 148-158.
- Mead, G.H. (1934). *Mind, self, and society*. Chicago: The University of Chicago Press.
- Mead, G.H. (1965). *On social psychology: Selected papers*. Chicago: University of Chicago Press.
- Melia, K.M. (1996). Rediscovering Glaser. *Qualitative Health Research*, 6, 368-378.
- Mitchell, G. & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing standard*, 30(7), 46-50.

- Montgomery, R.J.V., Holley, L., Deichert, J., & Kosloski, K.(2005). A profile of home care workers from the 2000 census: How it changes what we know. *The Gerontologist*, (45)5, 593-600.
- Morgan, D. L., & Krueger, R.A. (1993). When to use focus groups and why. In D.L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 35-50). Newbury Park, CA: Sage Publications, Inc.
- Morgan, D.L. (2010). Asking questions in focus groups. Notes from Qualitative Methods Workshop, University of Alberta.
- Morgan, D.G., Stewart, N.J., D'Arcy, C., Forbes, D., & Lawson, J. (2005). Work stress and physical assault of nursing aides in rural nursing homes with and without dementia special care units. *Journal of Psychiatric and Mental Health Nursing*, 12, 347-358.
- Morse, J.M.(2001). Situating grounded theory within qualitative research. In R.S. Schreiber & P.N. Stern (Eds.), *Using grounded theory in nursing* (pp.1-17). New York: Springer Publishing Company.
- Nakhnikian, E., Wilner, M.A., Joslin, S., & Hurd, D. (2002). Nursing assistant training and education: what's missing? Retrieved from www.nursinghomesmagazine.com, June 2002, 48-51.
- Neisser, U. (1988). Five kinds of self-knowledge. *Philosophical Psychology* 1(1): 35-59.
- Orange, J.B. (2001). Family caregivers, communication, and Alzheimer's disease. In M.L. Hummert and J. Nussbaum (Eds.), *Aging, communication and health: Multidisciplinary perspectives* (pp. 225-248). Mahwah, NJ: Laurence Erlbaum Associates.

- Orange, J.B., Ryan, E.B., Meredith, S.D., & MacLean M.J. (1995). Application of the communication enhancement model for long-term care residents with Alzheimer's disease. *Topics in Language Disorders, 15*(2), 20-35.
- Osburn, J. (2006). An overview of Social Role Valorization theory. *The SRV Journal, 1*(1), 4-13
- Passalacqua, S.A., & Harwood, J. (2012). VIPS communication skills training for paraprofessional dementia caregivers: An intervention to increase person-centered dementia care. *Clinical Gerontologist, 35*(5), 425-445.
<https://dx.doi.org/10.1080/07317115.2012.702655>
- Patient Restraints Minimization Act, 2001,S.O.2001,c.16
 Retrieved from <https://www.ontario.ca/laws/statutes/01p16>
- Polatajko, H. (2014). A call to occupationology. *Canadian Journal of Occupational Therapy, 81*(1), 4-7.
- Portney, L. G., & Watkins, M.P. (1993). *Foundations of clinical research: Applications to practice*. Stanford, Connecticut: Appleton & Lange.
- Post, S. G. (2000). Key issues in the ethics of dementia care. *Neurologic Clinics 18*(4),1011-1022.
- Pulsford, D., Duxbury, J., & Carter, B. (2016). Personal qualities necessary to care for people with dementia. *Nursing Standard, 30*(37), 38-44.
- Race, D., Boxall, K & Carson, I. (2005). Towards a dialogue for practice: Reconciling Social Role Valorization and the Social Model of Disability, *Disability & Society, 20*(5), 507-521. <https://dx.org/doi/10.1080/09687590500156196>
- Reber, A. S. (1995). *Dictionary of psychology*. New York: Penguin Books.

- Red River College. (2016). *Health care aide courses and descriptions*. Retrieved from <http://me.rrc.mb.ca/catalogue/CourseDescriptions.aspx?ProgCode=HEACP-CT&RegionCode=WPG#HCAP-1006>
- Robertson College. (2017). *Health care aide course outline*. retrieved from www.robertsoncollege.com/winnipeg-outlines/
- Romanchuk, R. (2008). Identification and accommodation of vulnerable populations in human research. *Research Practitioner*, 9(5), 158-171.
- Ruckdeschel, K. & Van Haitsma, K. (2004). A workshop for nursing home staff: Recognizing and responding to their own and residents' emotions. *Gerontology & Geriatrics Education*, 24(3), 39-51.
- Ryan, E.B., Byrne, K., Spykerman, H., & Orange, J.B. (2005). Evidencing Kitwood's personhood strategies: Conversations as care in dementia. In Boyd, H. Davis (Ed.) *Alzheimer talk, text and context* (pp. 18-36). Charlotte: University of North Carolina
- Ryan, E.B., Giles, H., Bartolucci, G., & Henwood, K. (1986). Psycholinguistic and social psychological components of communication by and with the elderly. *Language and Communication*, 6, 1-24.
- Ryan, E.B., Hummert, M.L., & Boich, L.H. (1995). Communication predicaments of aging: Patronizing behaviors toward older adults. *Journal of Language and Social Psychology*, 14 (1-2), 144-166.
- Ryan, E.B., Meredith, S.D., MacLean, M.J., & Orange, J.B. (1995). Changing the way we talk with elders: Promoting health using the Communication Enhancement Model. *The International Journal of Aging and Human Development*, 41(2), 89-07.

- Sabat, S., & Harre, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Aging and Society, 12*, 443-461.
- Salvatori, P.(1999). Meaningful occupation for occupational therapy students: A student-centered curriculum. *Occupational Therapy International, 6*(3), 207-223.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.
- Schechtman, M. (2005). Personal identity and the past. *Johns Hopkins University Press, 12*(2), 10-22.
- Schirm, V., Albanese, T., Garland, T.N., Gipson, G., & Blackmon, D.J. (2000). Caregiving in nursing homes: Views of licensed nurses and nursing assistants. *Clinical Nursing Research, 9*(3), 280-297.
- Siegler, I. C., Dawson, D.V., Welsh, K.A. (1994). Caregiver ratings of personality change in Alzheimer's disease patients: A replication. *Psychology and Aging 9*(3): 464-466.
- Small, J. A., Geldart, K., Gutman, G., & Clarke-Scott, M.A. (1998). The discourse of self in dementia. *Aging and Society, 18*, 291-316.
- Snellgrove, S., Beck, C., Green, A. & McSweeney (2015). Putting residents first: Strategies developed by CNAs to prevent and manage resident-to-resident violence in nursing homes. *The Gerontologist, 55*, (S1) S99-S107.
- Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott, Williams & Wilkins.
- Spike, J. (2000). Narrative unity and the unraveling of personal identity: Dialysis, dementia, stoke, and advanced directives. *Journal of Clinical Ethics, 11*(4), 367-372.

- Strauss, A. (1965). *George Herbert Mead on social psychology: Select papers*. Chicago: The University of Chicago Press.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Islands, CA: Sage Publications, Inc.
- Tappen, R., & Williams, C. (1998). Attribution of emotion in advanced Alzheimer's Disease: Family and caregiver perspectives. *American Journal of Alzheimer's Disease*, 13 (5), 257-264.
- Tappen, R. M., Williams, C., Fishman, S., & Touhy, T. (1999). Persistence of self in advanced Alzheimer's disease. *Image: Journal of Nursing Scholarship*, 31(2): 121-125.
- Taylor, S.J. & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance. *Disability, Handicap & Society*, 4(1), 21-36. <https://dx.doi.org/10.1080/02674648966780021>
- Taylor, S.J. & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource* (3rd ed.). New York: John Wiley & Sons, Inc.
- The Health Services Insurance Act (2015). Assented to 1992 by the Legislative Assembly of Manitoba. Current version in effect since November 5, 2015. Retrieved from http://web2.gov.mb.ca/laws/statutes/index_ccsm.php
- The Personal Care Homes Standards Regulation (2005). Regulations amending the Health Services Insurance Act (1992)). Retrieved from http://web2.gov.mb.ca/laws/regs/current/_pdf-regs.php?reg=30/2005
- The Personal Health Information Act (2013). Assented to June 28, 1997 by the Legislative Assembly of Manitoba. Current version in effect since December 5, 2012. Retrieved from http://web2.gov.mb.ca/laws/statutes/index_ccsm.php

The Protection of Persons in Care Act (2009). Assented to March 15, 2013 by the Legislative Assembly of Manitoba. Retrieved from

http://web2.gov.mb.ca/laws/statutes/index_ccsm.php

The Regional Health Authorities Act (2014). Assented to September 2, 2014 by the Legislative Assembly of Manitoba. Retrieved from

http://web2.gov.mb.ca/laws/statutes/index_ccsm.php

Thomson, M. & Burke, K. (1998). A nursing assistant training programs in a long term care setting. *Gerontology & Geriatrics Education*, 19(1), 23-35.

Thorne, S.(2008). *Interpretive description*. Walnut Creek, California: Left Coast Press, Inc.

Touhy, T.A. (2004). Dementia, personhood, and nursing: Learning from a nursing situation. *Nursing Science Quarterly*, 17(1), 43-49.

Townsend, E.A., & Polatajko, H.J. (2013). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation*. Ottawa: CAOT Publications ACE.

Van Vracem, V., Spruytte, N., Declercq, A., & Van Audenhove, C. (2016). Agitation in dementia and the role of spatial and sensory interventions: experiences of professional and family caregivers. *Scandinavian Journal of Caring Sciences*, 30, 281-289.

<https://dx.org.doi:10.1111/scs.12240>

Wilcock, A.A. (1998). *An occupational perspective of health*. Thorofare_NJ: SLACK.

Winnipeg Regional Health Authority. (2004). *Position description: Health care aide*. Winnipeg, MB.

Winnipeg Health Authority. (2012). *About P.I.E.C.E.S*. Retrieved from www.wrha.mb.ca/wave/2012/01/about-pieces.php

Winnipeg Regional Health Authority (2015). *Restraints in personal care homes (safe use of)*.

Winnipeg, MB.

Winnipeg Regional Health Authority (2016). Basic nonviolent crisis intervention training for

WRHA Employees 2016 (Brochure).

Retrieved from www.wrha.mb.ca/osd/files/2016NVCBrochure.pdf

Winzelberg, G.S., Williams, C.S., Preisser, J. S., Zimmerman, & Sloane, P.D. (2005). Factors

associated with nursing assistant quality-of-life ratings for residents with dementia in

long-term care facilities. *The Gerontologist Society of America*, 45(1). 106-114

Wolf, L. (2006). *Perceptions of personhood and the person with dementia. (Unpublished*

master's thesis). Dalhousie University. Halifax, Nova Scotia.

Wolf, L., & Orange, J.B. (2009). The application of communication enhancement and an

occupational therapy conceptual model of practice. Unpublished manuscript.

Wolfensberger, W. (2013). Social Role Valorization: A proposed new term for the principle of

normalization. *Mental Retardation*, 21(6)234-39.

Workplace Education Manitoba (2009). *Essential skills*. Retrieved from

<http://www.wem.mb.ca/uploads/HCA%20Introduction.pdf>

World Health Organization (WHO). (2001). *International classification of functioning, disability and health*. Geneva: Author.

Appendix A

Consent Form for Participation in an Individual Interview



Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Consent Form for Participation in Individual Interviews

Attached to this page is the **Consent Form** for this research study. Your participation in the study requires that you sign this form.

- **Please read this document carefully.** It will give you the information you need so you will understand what you are agreeing to do.
- **You may want to ask someone you trust to read this consent form with you.**
- If you or that person has questions about the research, you should contact **Lynda Wolf**.

Please bring the consent form with you when you meet with Lynda.



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate,

Consent Form for Participation in an Individual Interview

This consent form will give you the basic idea of what my research is about and what your participation will involve. If you would like more detail about something mentioned here or information that is not included in the form, you should feel free to ask me. Please take the time to read this carefully so you understand what you are agreeing to do. You will get a copy of this consent form for your records.

Purpose of the Research

I am a graduate student at the University of Manitoba, and this study is being carried out as part of my PhD program.

This research is about how health care aides who work with residents with dementia feel about and understand these residents. I want to explore how these feelings and understandings affect how health care aides talk to residents with dementia and act towards them.

Voluntary Participation

Your participation in my research is voluntary.

You may agree to take part in an interview with me. You do not have to answer all the questions or give me any information that you do not want to share. If you are uncomfortable answering a question, I will move on to another question. You may withdraw from the study at any time.

You will experience no negative consequences should you decide not to participate or to withdraw from the study at any time.

Research Procedures

There are two stages of this study in which you are invited to participate.

This consent form is for participation in Stage 1.

In the first stage, I, Lynda Wolf, will interview you by yourself. I will ask you questions about your thoughts and feelings about residents you care for who have dementia. I will also ask you questions about how these thoughts and feelings affect how you talk to these residents and act towards them.

The interview will take about an hour and a half (90 minutes) and will occur at a place that is convenient to you outside. If your facility permits, the interviews may occur during working hours. Otherwise, the interview will occur outside of your regular working hours.

You will receive ten dollars for participating in an individual interview to help cover the cost of transportation or parking or other expenses you might experience as a result of participating in this interview.

Potential Risks and Benefits

You may get emotional as you talk with me about your thoughts and feelings about residents with dementia. If this happens, you can tell me about this. I will stop the interview at this time. You may decide to continue with the interview after expressing these feelings but you are under no obligation to do this. If you wish, I can provide you with the telephone number of your Employee Assistance Program.

The findings of this study may have benefits to you and other health care aides. The study results may give information to teachers about how to best help health care aides understand communication with residents who have dementia. The findings may also help managers and supervisors and other team members understand how health care aides think and feel about these residents as they provide care.

Data Collection

The interview with me alone will be recorded with a combination of both a portable tape recorder (Sony M-200 MC) and a digital recording device (Olympus WS-500). Both of these devices record only what you and I say. The information recorded by the digital recording device will be saved on an encrypted storage device (SanDisk Ultra Backup 64 GB USB 2.0 Flash Drive). If you do not want to have your conversation recorded, I will take written notes.

Confidentiality

I will use a code number instead of your name to identify the information that you give me. The demographic form will also have this code number instead of your name. When I use the findings of this study in reports or presentations, all information that could identify you, such as your name or place of work, will be removed.

A professional transcriber will type the recorded information from either the tapes from the tape recorder or the digital recording device. During this process, he/she will use ear phones so that no one can overhear what has been said. All transcribed information will be saved on the encrypted storage device. Only the transcriber, some members of my committee, and I will have access to the tapes and recorded information saved on this device. My computer is password-protected and only I have access to this computer. All typed information will be kept in a locked

filing cabinet in my office. Only I and the members of my committee will be able to see the typed information.

The master list which matches your name to the code number for your interview will be kept separately from the typed information in a locked drawer in my office. I will be the only one to have access to the master list that contains your name and code number. Your consent form with your name on it will be kept separately from the data in a drawer in the locked filing cabinet.

After I have taken the information from the encrypted storage device, the storage device, tapes and demographic form will be stored in a locked filing cabinet. I will retain these, along with the master list and consent form for up to seven years. At that time all forms and typed information will be destroyed. At the same time, the information on the tapes and any information retained on the storage device will be erased.

If in the course of our interview I become aware of abuse or neglect to residents, I am required by law to report this abuse to the Office of the Protection of Persons in Care.

Feedback

You can inform me that you want to receive a brief report about the study by signing the *Request to Receive Study Findings* at the end of this form. This will require that you give me an address to let me know where to send the findings. This list will be kept with the other information related to your participation in this study and will be stored separately from the data in a locked filing cabinet.

Your continued participation should be as informed as when you initially agreed to participate in the study. You should feel free to ask for clarification or new information throughout your participation in the study. Therefore, you should feel free to ask me if you need more information throughout the study or to contact members of my committee for the information.

Principal researcher

Lynda Wolf

Supervisors' Names and Contact Information:

Pamela G. Hawranik, RN, PhD
Professor & Dean, Faculty of Graduate Studies
Athabasca University

Marie Edwards, RN, PhD
Assistant Professor
Faculty of Nursing, University of Manitoba

This research has been approved by the Education/Nursing Research Ethics Board of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat

A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature:

Date: _____

Researcher Signature

Date _____

Stage Two of this Study

If you agree to participate in Stage two of this research study, it will involve taking part in a group interview with other health care aides from this facility. This interview will be conducted by me and a research assistant. It will take about two hours and will occur at a place that is convenient to the health care aides who agree to participate. This group interview will occur outside of your regular working hours.

I will use the analysis of the interview with you and other health care aides to develop the questions for this group interview. The purpose of this group interview will be to provide me with feedback about how well I have perceived the information that you and other health care aides have given me during individual interviews.

Do you agree to being contacted by either me or a research assistant regarding possibly taking part in one group interview with other health care aides from the facility in which you work?

Yes ___ No ___

If there are not enough volunteers for the focus group, do you agree to be contacted by me or a research assistant about being interviewed by me in a second individual interview?

Yes ___ No _____

Preferred route of contact:

Phone _____

E-mail _____

Request to Receive Study Findings

I _____ (please print) request that a copy of the findings from this study be sent to me by either mail or e-mail at the following address.

Mailing Address

Email Address: _____

Participant's Signature: _____

Date: _____

Appendix B

Consent Form for Participation in a Group Interview



Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Consent Form for Participation in a Group Interview

Attached to this page is the **Consent Form** for this research study. Your participation in the study requires that you sign this form

- **Please read this document carefully.** It will give you the information you need so you will understand what you are agreeing to do.
- **You may want to ask someone you trust to read this consent form with you.**
- If you or that person has questions about the research, you should contact **Lynda Wolf**

Please bring the consent form with you when you meet with Lynda.



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate,

Consent Form for Participation in a Group Interview

This consent form will give you the basic idea of what my research is about and what your participation will involve. If you would like more detail about something mentioned here or information that is not included in the form, you should feel free to ask me. Please take the time to read this carefully so you understand what you are agreeing to do. You will get a copy of this consent form for your records.

Purpose of the Research

I am a graduate student at the University of Manitoba, and this study is being carried out as part of my PhD program.

This research is about how health care aides who work with residents with dementia feel about and understand these residents. I want to explore how these feelings and understandings affect how health care aides talk to residents with dementia and act towards them.

Voluntary Participation

Your participation in this group interview is voluntary.

If you agree to take part, you and other health care aides from your facility will be interviewed by me. You do not have to answer all the questions during the group interview or share any information with the group that you do not want to share. You may withdraw from the group discussion at any time. You will experience no negative consequences should you decide not to participate in the group interview.

Research Procedures

This study is made up of two stages. You have already participated in Stage I when you were interviewed by me.

You are being invited to take part in the second stage of this study.

This is the consent form for Stage 2. If you agree to participate in this second stage, you will take part in a group interview with me and other health care aides from your facility. These health care aides have also been interviewed by me.

If there are not enough volunteers for the focus group, you will be asked to be interviewed by me in a second individual interview.

This interview will take about two hours and will occur outside of your regular working hours. It will occur in a place that is convenient to the health care aides who participate. It might be a room in this facility or some place outside the facility that is convenient to you.

A research assistant will be present to help me conduct the interview. This research assistant will contact you a few days before the interview to remind you of the date and location and to ask you if you are still willing to participate in the group interview.

You will receive ten dollars for participating in the interview.

Potential Risks and Benefits

You may become emotional as you talk with the other health care aides in the group about your thoughts and feelings about residents with dementia. Other members of the interview group will recognize you and will hear what you have to say. This may also cause you feelings of discomfort.

In the case that you experience discomfort talking about your thoughts and feelings during the interview, you may leave the interview. If you wish, the research assistant will be available to discuss these feelings with you outside of the interview room. You can then decide if you want to return to the interview or if you want to leave. If you decide to leave the interview, I will contact you a day or two following the interview by phone or email to find out how you are. At that time, you will be given the opportunity to discuss your feelings of distress with me. If you wish, I can also provide you with the telephone number for contacting you Employee Assistance Program.

The findings of this study may have benefits to you and other health care aides. For example, the study results may give information to teachers of health care aides about how to teach courses that help health care aides understand how to talk and interact with residents with dementia. The findings may also help managers and supervisors and other health care team members to understand how health care aides think and feel about these residents as they provide care.

Data Collection

I will ask questions that I have developed from the analysis of what you and other health care aides have told me during the individual interviews. However, as we discuss these questions, other topics may arise about your thoughts and feelings about working with people with dementia. We can discuss these questions as well.

During this group interview, a research assistant will take notes that will help me recall the details of our discussion. The research assistant will assign a number to your location in the room and will not identify you by name in these notes.

The group interview will last about two hours. The interview will be audiotaped. Only what you say will be recorded. The recorded information will be saved on an encrypted storage device (SanDisk Ultra Backup 64 GB USB 2.0 Flash Drive).

I will attempt to keep the location of the interview confidential. The location of the interview, and its date and time will be chosen to be convenient to the participants.

Refreshments will be available throughout the interview.

Confidentiality

I will use a code number instead of your name to identify the information that you give me. When I use the findings of this study in reports or presentations, all information that could identify you, such as your name and place of work, will be removed.

All participants of the focus groups will be required to sign a pledge of confidentiality promising to keep confidential all matters related to the group interview, including the names and identities of the group participants.

The research assistant has signed a pledge of confidentiality promising to keep confidential anything that he/she hears during the interview.

A professional transcriber will type the recorded information from the recording device. During the typing process he/she will use ear phones so that no one can overhear what has been said. All transcribed information will be saved on the encrypted storage device. Only the transcriber, some members of my committee and I will have access to the tapes and the recorded information on this device. My computer is password-protected and only I have access to this computer. All typed information will be kept in a locked filing cabinet in my office. Only I and the members of my committee will be able to see the typed information.

The notes taken by the research assistant will be kept in this locked filing cabinet with transcripts from the interviews.

Your consent form with your name on it will be kept separately from the data in a drawer in the locked filing cabinet.

After I have taken the information from the encrypted storage device, the storage device and tapes will be stored in a locked filing cabinet. Your consent form will be stored separately from the data. After seven years, all forms and typed information will be destroyed. At the same time, the information on the tapes and any information retained on the storage device will be erased..

If I become aware of abuse or neglect to residents, I am required by law to report it to the Office of the Protection of Persons in Care.

Feedback

You can inform me that you want to receive a brief report about the study by signing the *Request to Receive Study Findings* at the end of this form. This will require that you give me an address to let me know where to send the findings. This list will be kept in a safety deposit box and will be destroyed within a year after the study has been completed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in this research project and you agree to be a participant in the group interview. In no way does this take away your legal rights or the rights of researchers, sponsors, or facilities from their own professional and legal responsibilities.

You should feel free to ask me if you need more information throughout the study.

Principal researcher

Lynda Wolf

Supervisors' Names and Contact Information:**Pamela G. Hawranik, RN, PhD**

Professor & Dean, Faculty of Graduate Studies
Athabasca University

Marie Edwards, RN, PhD

Assistant Professor
Faculty of Nursing, University of Manitoba

This research has been approved by the Education /Nursing Research Ethics Board of the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat

A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature:

Date: _____

Researcher Signature _____

Date: _____

Request to Receive Study Findings

I _____ (please print) request that a copy of the findings from this study be sent to me by either mail or e-mail at the following address.

Mailing Address

Email Address: _____

Participant's Signature: _____

Date: _____

Appendix C

Letter to Long-term Care Facility Chief Executive Officer



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Name of CEO or other appropriate contact person

Name of Facility

Address of Facility

My name is Lynda Wolf and I am A PhD student in the Applied Health Sciences program at the University of Manitoba. I am also anon-practicing occupational therapist with many years of experience working health care aides as they provided care to residents with dementia.

As part of the requirements for the completion of my degree, I am conducting a research project about how health care aides think about and understand residents with dementia. In this study, I will attempt to identify a linkage between the thoughts and understandings of these staff members and the way they interact with residents with dementia.

I am now in the process of locating sites in which to conduct this research. I am contacting you to see if you would be interested in permitting me to conduct this study in your facility. Specifically, I am requesting research access to your facility so that I might recruit health care aides employed by you to be interviewed individually and in a focus group. The participation of health care aids in this study is voluntary. Health care aides who participate in this study will be required to read and sign a consent form indicating informed consent for each of these interviews. All information related to their participation in the study will be kept confidential.

In order to achieve variability of data, I plan to conduct this study in three different long term care facilities in this region.

This study has received ethics approval from the Education /Nursing Research Ethics Board of the University of Manitoba. Research access for this study has been granted by Dr. Metge, CHI Evaluation Platform, WRHA. However, I am aware that I would have to negotiate separate research access with your facility.

Health care aides provide over seventy per cent of the direct care to residents with dementia in personal care homes in the Winnipeg Regional Health Authority. The literature about dementia proposes that the way that health care aides talk to these residents and interact with them has a significant effect on the quality of life of these residents. The findings of this study may have direct applicability in facilities such as yours in promoting the effectiveness of health care aide interactions with residents with dementia. The results of this study may also be used by colleges that train health care aides to better prepare them for talking and interacting with residents with dementia.

Would it be possible to meet with you to discuss the possibility of this study being conducted in your facility? If you think this is a possibility, I would be happy to meet with you at your convenience.

Yours truly,

Lynda Wolf
PhD Candidate

Appendix D
Information about the Study



UNIVERSITY
OF MANITOBA

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Faculty of Graduate Studies
Applied Health Sciences

**Research Title: Communication Interactions of Health Care Aides and Individuals with
Dementia**

Researcher: Lynda Wolf, PhD Candidate,

Information about the Study

This study about the communication interactions of health care aides and individuals with dementia residing in long term care facilities is being undertaken as my thesis for meeting the requirements of the Applied Health Sciences Programs at the University of Manitoba. I am currently a PhD Candidate in this programs. As well, I am a non-practicing occupational therapist. While in active practice, I had many years' experience working with health care aides as they provided care to residents with dementia. As a result of my experience working with health care aides, I am convinced of the importance of the interactions of health care aides in promoting the communication, function and well-being of residents with dementia.

Health care aides provide over seventy per cent of the direct care to residents with dementia in personal care homes in the Winnipeg Regional Health Authority. The literature about dementia proposes that the way that health care aides talk to these residents and interact with them has a significant effect on the communication skills, functional performance and quality of life of these residents.

This grounded theory study will explore how health care aides think about and understand residents with dementia. It will attempt to identify a linkage between the thoughts and understandings of these staff members and the way they interact with residents with dementia.

I am recruiting health care aides with experience working with residents with dementia and who are employed in personal care homes in Winnipeg to participate in this study. In collecting data for the study, I will interview individual health care aides about their thoughts and understandings of the residents in their care. After the initial stages of data analysis, I would like to conduct focus groups with these same health care aides. Each focus group will involve health care aides from the same facility. The purpose of the focus group will be to help confirm my preliminary findings as well as to uncover new data. If there are insufficient numbers of volunteers for a focus group in any of the facilities, any of the participants who volunteer will be contacted to see if he/she agrees to a second individual interview. With the permission of the facility, some interviews may occur within working hours. Otherwise, all interviews and focus groups will occur outside of the health care aide's regular working hours and will therefore take place on the participant's own time.

The results of this study will be used to develop a theory that describes and explains the interactions of health care aides with residents with dementia. These findings may be used by colleges that train health care aides to better prepare them for talking and interacting with residents with dementia. The findings may also be useful to managers in supervising and working with the health care aides on their teams. Other team members may also benefit from these findings.

All participation in this study is voluntary. There will be no negative consequences to health care aides who refuse to participate. Health care aides who do agree to participate in these interviews may leave the interview process at any time. Confidentiality will be maintained. No names or identifying information will be used in any presentations or publications that arise from this study.

If you are interested in finding out more about the study or would like to take part as a study participant, I will be pleased to talk with you.

Please contact Lynda Wolf

Appendix E

Script for Meeting with Health Care Aides



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Script for Meeting with Health Care Aides

(This script will be used in face to face meetings with health care aides and when talking with them on the telephone. A copy of this script will be sent by email if requested by a health care aide.)

Thank you for (agreeing to meet with me) (contacting me).

My name is Lynda Wolf. I am a PhD student in the Applied Health Sciences PhD program at the University of Manitoba. I am conducting a research project about how health care aides interact with residents with dementia as part of the requirements for graduation from this program. The name of this study is *Communication Interactions of Health Care Aides and Individuals with Dementia*.

I am a non-practicing occupational therapist who has worked for a number of years with residents with dementia in a long term care facility here in Winnipeg. I have worked with many health care aides like you. I understand the important contribution that you make to the care of your residents. Did you know that between 70-90% of the direct care provided to residents in personal care homes is provided by health care aides?

Since you spend so much time with residents with dementia, you are the people who have the greatest amount of interaction with these residents. This study is about how you see and

understand the residents you work with and how this affects how you communicate and interact with these residents.

I am asking you to participate in this study. Your participation in this study is completely voluntary. There are no negative consequences if you decide not to participate.

There are two stages to your participation should you agree to take part.

- In the first stage, I would interview you alone.
- This interview will take about an hour and a half and will occur outside of your regular working hours.
- The interviews will be recorded using a digital recorder that will only record your voice. However, if you don't want to be recorded, I would take notes of what you tell me. This interview will take about an hour and a half.

After the individual interview, you will be asked to take part in a group interview with other health care aides who work at your facility and whom I have interviewed.

- This interview will take place at a time and location convenient to you.
- The group interview will take place outside of your regular working hours.
- During this group interview, I will ask you questions that have come from the analysis I have completed of the information you and others gave me in the individual interviews.
- This will be a way you can tell me if I understood what you told me and if I "got it right". During this group interview, you might also tell me information that you hadn't thought of before.
- If there are not enough volunteers for a focus group in any of the facilities and you have volunteered for the focus group interview, you will be contacted to see if you agree to a second individual interview.

More about the Group Interview

- The group interview will take about two hours.
- One of the things you might want to consider about participating in the group interview is that the other members of the group are health care aides who work here and who you know. It might be uncomfortable for you to talk openly about your experiences with residents in front of your colleagues (co-workers).
- However, everyone who takes part in the group interview will be asked to sign a pledge of confidentiality and agree not to tell others who participated in the group or what was said during the interview.
- If you agree to participate, you will have to read and sign a consent form that tells you about the study.
- You will also be asked to complete a form that asks questions about your background, including the languages you speak and your educational background.
- You can withdraw from the study at any time.
- All information about you and what you say will be kept confidential. For example, I will use a code number instead of your name to identify the information that you give me.

When I use the findings of this study in reports or presentations, all information that could identify you, like your name, will be removed.

You will receive ten dollars for each interview in which you participate to help cover any costs you experience from participating in the interview.

By participating in this study, you will have a unique opportunity to talk about your experiences as a health care aide in communicating with residents with dementia. For example, you will be able to tell me the things that you have found to work and not work. Only health care aides are being interviewed in this study. This study is really about you.

If you participate in the study, you can receive a summary of the findings.

The findings from this study

- May be used by colleges that train health care aides.
- May also be used by managers and administrators who hire and supervise you.

Therefore, by participating in this study, you can contribute to how other health care aides are educated and supervised.

Risks associated with Participating

- You might feel distressed about what you are telling me about your work with residents with dementia.
- If this happens, we can talk about this and you might decide to end the interview. You are free to withdraw from the study at any time.

I hope that you will think seriously about taking part in this study. If you want more information, you can call me by telephone or email me. My telephone number and email address are on this information sheet and on a poster that I will leave on your unit.

If you agree to take part in the study, we will set up a time to meet that is at your convenience.

I am leaving copies of the consent form in a box that has the title of the study and my name written on it in (name/location of room). You will need to read and complete a consent form and bring it with you when you come to the interview. You may also want to go over the consent form with someone you know and trust to discuss what it means to you to take part in this study.

If you cannot locate a copy of the consent form,

- Please contact me again and I will mail a copy to you.
- However, you will then have to agree to provide me with a mailing address to which I can send the form.

You can always contact me to discuss the consent form. I will be happy to discuss any of the information about the study and consent form with you.

Again, please consider being interviewed for this study. This study is really about you and the important work you do.

Thank you for agreeing to meet with me.

Appendix F

Script for Meeting with Unit Managers



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate,

Script for Meeting with Unit Managers

My name is Lynda Wolf and I am a PhD student in the Applied Health Sciences program at the University of Manitoba. I am also a non-practicing occupational therapist. Before my retirement, I had with many years' experience working health care aides as they provided care to residents with dementia.

As part of the requirements for the completion of my degree, I am conducting a research project about how health care aides think about and understand residents with dementia. The title of this study is *Communication Interactions of Health Care Aides and Individuals with Dementia*. In this study, I will attempt to identify a linkage between the thoughts and understandings of these staff members and the way they interact with residents with dementia.

Your facility has given me permission to recruit health care aides to participate in this study. There are two stages to participation in this study. In Stage One, the participant will participate in an individual audio-taped interview with me. Stage Two involves participation in a focus group with other health care aides from this facility. If there are insufficient numbers of volunteers for a focus group, those who do volunteer will be asked to participate in a second individual interview. With the permission of the facility, some interviews may occur within working hours. Otherwise, all interviews and focus groups will occur outside of the health care aide's regular working hours and will therefore take place on the participant's own time.

I am requesting the following assistance from you.

- Recruiting health care aides to participate in this study. I would like to meet with health care aides at a convenient time, such as a staff meeting or break time, to explain the study and invite these staff members to participate in this study. I would like to meet with health care aides on each of the shifts throughout the 24 hour day. This meeting would

take about fifteen minutes. I will only meet once with the staff on each shift. I will only meet once with the staff on each shift for a total of three meetings over the 24 hour day.

- Permission to put posters up on your unit advertising the study to health care aides.
- Permission to leave information sheets and consent forms on the units. The consent forms would be left in a cardboard box identified with my name and the title of the study.

This study provides an important opportunity for health care aides to participate in research that can have a direct impact on the care they provide to residents with dementia.

I hope that you will be able to provide the assistance that I am requesting.

At the request of your facility, I will be pleased to provide your facility with a copy of the findings. I will also be available to make a presentation of the study findings to staff.

Appendix G

Poster

Attention Health Care Aides

You are invited to take part in a research study about health care aides who work with residents with dementia.

The researcher is Lynda Wolf. She is a PhD student at the University of Manitoba. She wants to interview health care aides who work with residents with dementia. Her purpose is to explore how the thoughts and feelings of health care aides about these residents affect the way they talk to residents and interact with them.

YOU have the insights needed for this study
YOU are being **INVITED** to participate

If you want to know more about **HOW** you can participate in this study, please contact:

Lynda Wolf

Appendix H

Interview Questions for Individual Interviews with Health Care Aides



UNIVERSITY
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Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Interview Questions for Individual Interviews with Health Care Aides

Tell me about how you decided to become a health care aide?

Probing questions:

- Did someone suggest that you would be good at taking care of people?
- Did you help to take care of family members or friends before you made this decision?
- Did you want to take care of people?
- Did you try other things first?
- Did you need a job and this one came along?

Tell me about what it is like working as a health care aide in this facility.

Probing questions:

- What made you decide to work in this place?
- What do you like most about being a health care aide?
- What makes you feel good about your job here? What do you not like about being a health care aide?
- What are some of the things that might upset you during your day? (Too much work, conflict with other staff, something a resident does, etc.)

Would you tell me about your residents with dementia?

Probing questions:

- Do they all have dementia?
- How do you know they have dementia?

What do you know about dementia?

Probing questions:

- Do you know what causes dementia?
- How does it affect people?
- How do they look? How do they behave? How do they talk to you?

How would you describe the residents with dementia?

Probing questions:

- What do they look like?
- What do they say?
- What can they do? What are they not able to do?
- How do they behave?

How would you describe your feelings about these people?

Probing questions:

- What are your positive feelings about residents with dementia?

Can you describe these feelings?

When do you have these positive feelings?

What is going on when you have these good feelings about residents with dementia?

- How do you think these positive feelings affect how you act around these residents?
 - i. How do these positive feelings affect how you talk to these residents?
 - ii. How do you think these positive feelings affect how you act toward these residents? What you say? How you say it?
 1. Do you say more or less?
 2. Do you talk faster or slower? Louder or softer?
 3. Do you stand closer or further away from the resident?
 4. Do you ever use the same words that you use when you talk to children?

5. How do these residents react to what you say? Does how they react to what you say ever change the way you talk with them? For example, if they smile at you, do you say more?
 6. Would you like to spend more time talking with these residents?
- Do you have bad or negative feelings about residents with dementia?
 - iii. Can you describe these feelings?
 - iv. When do these feelings occur? What is going on?
 - Do residents with dementia ever threaten or hurt you?
 - v. How do you feel when they do this?
 1. Uncomfortable, frightened, repulsed or “turned off”, sorry for them, impatient
 2. How do you act toward a resident who hurts or threatens you? What do you say? How do you say it?
 3. How do you feel towards residents who have hurt you?
 4. What else would you like to tell me about how you think and feel about residents here with dementia?
 - 5.

Questions about Health Care Aides Providing Care to Residents with Dementia

I want you to think about when you are providing care to residents in the morning?

- How do you address the person? (Mr./Mrs./Miss; first name, nick name or by a special name you have for them?)
- What do you say to a resident when you are giving them care first thing in the morning? (Talk to them like you would talk to anyone else, do not talk to them much if at all, talk to them like a child you are caring for, etc.)
- How much do you say to these residents during care first thing in the morning? (Do you talk a lot? Not so much?) What affects how much you say? (Having a lot to do, having a positive or negative relationship with the resident; what you heard about the resident during morning report, how you are feeling that day, such as feeling tired or worried)
- What influences what you say? (Having a lot to do, having a positive or negative relationship with the resident; what you heard about the resident during morning report, how you are feeling that day, such as feeling tired or worried)
- What problems to residents with dementia present when you are providing care?
- How do you feel when these problems occur? What do you think about the resident when these problems occur? (it’s not the resident’s fault that they are ill’, the resident deliberately tries to make life difficult, etc.)
- What do you say when they don’t do what you want them to do?(Do you stop talking, repeat yourself,)

- How do you speak or interact with a resident who can't hear you? (Raise your voice, use more gestures and facial expressions, talk less, write things down, etc.)
- What do you say or do if they look like they might leave you or hurt you?
- What goes through your mind when you are trying to work with an uncooperative or abusive resident?(I wish I wasn't here; I am afraid I will get hurt; I want to calm this person down)
How do you figure out what to say?
- What else would like to say about talking to residents with dementia during morning care?

Questions about Health Care Aides interacting with Residents during a Mealtime

- What do you say to these residents during breakfast or other meals? (Talk a lot? Not so much?)
- What do you say to a resident who can't speak? (Don't talk; try to keep talking)
- How do you decide what to say? (What you know about the resident, how you feel that day, what you think the resident can hear or understand?)
- How much you say? (Don't talk, try to talk)
- How do you decided how much to say? (The resident may look tired; resident may look more alert; you don't feel like talking; you never know what to say and don't say much)

Here are some general questions about talking or just being with residents with dementia.

- Do you think you change your way of speaking to residents when you are busy? (The amount you say. What you say? The tone of your voice? The way that you address them as, for example, "Mr.", "Mrs", or by first name, nick name, special name)
- What things might happen to you in your day that might change how you talk to residents?
- Earlier, you said that _____ are some of the problems you have during your working day. When _____ happens, does it change how you talk to residents with dementia? In what way do you speak differently to residents (Say less, say more, talk louder, use shorter sentences, show your emotions more, use a different way of addressing the resident. Some other changes in the way you speak to residents?)
- Do you think how you talk to the residents makes a difference to them?

Thank you for answering my questions. What you have to say has been very helpful for this study.

Do you have any questions?

Thank you again.

Appendix I
Focus Group Interview Guide



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate

Focus Group Interview Guide

Greeting and Opening Remarks

Thank you for agreeing to participate in this group interview.

This focus group will be conducted by me, Lynda Wolf and _____ [research assistant], who will be assisting with this group interview.

This group interview is Stage 2 of the research project I am conducting as a PhD student at the University of Manitoba.

This research is about how health care aides who work with residents with dementia feel about and understand these residents. I want to find out how these feelings and understandings affect how health care aides such as you talk to residents with dementia and act towards them.

Your participation in this group is entirely voluntary. You may leave at any time during the group interview.

This interview is going to be audio-recorded. As well, the Research Assistant will be taking some notes during the interview. I will make every attempt to keep your identity and everything that you say confidential.

If, during this group discussion, you experience feelings of distress, you can let _____ [research assistant] and I know. You and _____ [research assistant] can leave to talk privately. If you want, you can leave the interview or return to the group. That decision will be up to you.

Pledge of Confidentiality

I have given each of you a form that is a *Pledge of Confidentiality*. To participate in this group interview, you must read and sign this pledge. When you sign this form, you are promising not to repeat anything that is said here. Are there any questions about the form?

Ground Rules (adapted from Krueger & Casey, 2009)

Here are some points to remember for our discussion:

- In this discussion, there is no right or wrong answer.
- If you want to respond to what someone else has said, if you want to agree or disagree, for example, please feel free to do so.
- We want to hear what everyone has to say.

Introduction to Interview

I have interviewed each of you separately. You have each provided valuable information and insights about how you communicate with residents with dementia.

After each interview, a transcriber typed out what you told me into a transcript. I analyzed each transcript to find what I thought were the most important ideas. When I found ideas that seemed similar, I put them together into a category and gave that category a name. When I began to link these categories together, I thought I was getting a better understanding of the meaning of what you had told me.

Now I am meeting with you to ask you some more questions to see if I am on the right track.

Introductory Question

Although you and I have talked before, _____, my assistant, has not met you. Would you tell us your name? Would you also tell the group what comes to your mind first when you hear the word “dementia”?

Transition Questions

As you know, we are here to talk about communication and persons with dementia.

How do you think the way you communicate with residents with dementia is important?

Why do you think this?

Sample Key Questions

(Two or three questions will be developed from the open and axial coding of the transcripts from all individual interviews conducted prior to this group interview. The interview will follow a script similar to that provided below.)

When I analyzed the transcripts from your interviews, I found (two or three) themes about your communication with residents with dementia that I would like to follow up with you during this interview.

I called the first theme

(One or two sentences will follow to explain what this category represents.)

I'd like to know what you think about this theme. For example, do you agree or disagree that this is an important concern for you when you are communicating with residents?

(Two or three questions will have been developed to stimulate discussion about this theme and to provide more information about the properties and dimensions of this category, using questions beginning with words such as "what", "why", "when", "who", or "how".)

The second theme that I found through analysis of the transcripts of your interviews was

Again, I'd like to know what you think about this theme.

For example, do you agree or disagree that this is an important concern for you when you are communicating with residents?

(Again, two or three questions will have been developed to stimulate discussion about this theme and to provide more information about the properties and dimensions of this category, using questions beginning with words such as "what", "why", "when", "who", or "how".)

Reflection

Here is a summary of what I heard you tell me during this group interview?

1. _____

2. _____

3. _____

Do you think this is correct? What else would you like to add?

Ending Questions

This is the last chance I have to talk with you about your interactions with residents with dementia? What have I missed? What else do you think I should know about how you work and communicate with residents with dementia?

Thank you for taking part in this group discussion. What you have told me here will certainly help me in going forward with this study.

Appendix J
Demographic Form



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Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with
Dementia

Researcher: Lynda Wolf, PhD Candidate,

Demographic Form

Thank you for participating in this study.

This grounded theory study will explore how health care aides think about and understand residents with dementia. It will attempt to identify a linkage between the thoughts and understandings of these staff members and the way they interact with residents with dementia.

The following information is being requested to provide the researcher, Lynda Wolf, with additional information for data analysis. This information will also help to determine how the findings of the study can be applied to other health care aides.

Please remember that all information is kept confidential and that the information you provide will not be identified with you.

Please complete this form before you come to the interview with Lynda Wolf.

Instructions:

This questionnaire has different types of questions:

a) Close-ended questions for which the correct response should be **check-marked** in the appropriate box.

b) Open-ended questions for which a response could be entered on the line provided.

Thank you for taking the time to answer these questions.

Participant Code Number _____

1. Gender

Male

Female

2. Age: ____

3. How would you describe your ethnic origin? _____

4. What was the first language you spoke? _____

5. What languages do you speak now? _____

6. What is your employment status at this facility? (Please circle)

Full-time Part-time Casual Other

7. The following questions are about your education.

7.1 What was the highest grade level you completed? _____

7.2 Do you have any educational training beyond high school equivalency?

Yes

No

7.3 If yes, what was the programs called? _____

7.4 Did you graduate from the programs?

Yes No

7.5 Do you have other professional training qualifications, such as Rehabilitation Attendant?

Yes No

7.6 What qualifications did you obtain? _____

7.7 If “yes”, where was this training obtained? _____

Thank you for completing this form

Appendix K

Confidentiality Pledge for Participants in a Group Interview



UNIVERSITY
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Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Researcher: Lynda Wolf, PhD Candidate,

Pledge of Confidentiality for Participants of the Group Interview

I, _____, agree to keep confidential all matters related to the Group Interview conducted by Lynda Wolf as part of this research project. I will not reveal the names or identities of participants in the group nor will I repeat anything that has been said during the group interview.

Signed: _____

Date: _____

Researcher: _____

Appendix L
Transcriber's Pledge of Confidentiality



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with Dementia

Researcher: Lynda Wolf, PhD Candidate,

Transcriber's Pledge of Confidentiality

I, _____, agree to keep confidential all matters related to this study. This will include any information of which I become aware through listening to the interview tapes, discussions with Lynda Wolf or members of her committee or by any other means.

Signed: _____

Date: _____

Researcher: _____

Appendix M
Confidentiality Pledge for Research Assistant



UNIVERSITY
OF MANITOBA

Faculty of Graduate Studies
Applied Health Sciences PhD Program

University of Manitoba
500 University Centre
Winnipeg, MB
Phone: (204) 474 9377

Research Title: Communication Interactions of Health Care Aides and Individuals with
Dementia

Researcher: Lynda Wolf, PhD Candidate,

Pledge of Confidentiality for Research Assistant

I, _____, agree to keep confidential all matters related to this study. I will not reveal the names or identities of any participants in the study nor will I reveal any information of which I become aware through attending the group interview, transcripts, discussions with Lynda Wolf or members of her committee, or by any other means.

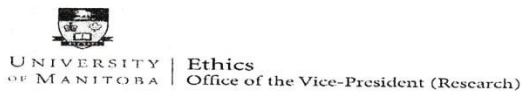
Signed: _____

Date: _____

Researcher: _____

Appendix N

Approval from Education and Nursing Research Ethics Board



CTC Building
208 - 194 Dufresne Road
Winnipeg, MB R3T 2N2
Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

April 4, 2011

TO: Lynda Wolf (Edwards/Hawranik)
Principal Investigator

FROM: [REDACTED]
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2011:017
"Communication Interactions of Health Care Aides and Individuals
With Dementia"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

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, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- 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 Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix O

Renewal Approval from Education and Nursing Research Ethics Board



Research Ethics and Compliance
Office of the Vice-President (Research and International)

Human Ethics
208-194 Dufour Road
Winnipeg, MB
Canada R3T 2N2
Phone (204-474-7122)
Fax (204-269-7173)

RENEWAL APPROVAL

May 1, 2014

TO: Lynda Wolf
Principal Investigator

FROM: [Redacted]
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2011:017
"Communication Interactions of Health Care Aides and
Individuals with Dementia"

Please be advised that your above-referenced protocol has received approval for renewal by the Education/Nursing Research Ethics Board. **This approval is valid for one year only.**

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.