

**Person-Centered Care Practices and Organizational
Issues in Long-Term Care Facilities:
A review and synthesis of the literature**

**by
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B.B.A, University of Texas at Arlington, 2007

Project Submitted in Partial Fulfillment of the
Requirements for the Degree of
Master of Arts

in the
Department of Gerontology
Faculty of Arts and Social Sciences

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SIMON FRASER UNIVERSITY
Fall 2016

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Abstract

Care practices in long-term care facilities have typically been guided by the biomedical approach to care. In the past two decades, there has been a growing movement in transforming care for residents from a medical model to a person-centered model in long-term care. This capstone project reviews and synthesizes current literature on person-centered care, with a focus on care practices and organizational issues. An extensive literature review was conducted using databases such as Ageline, PsychINFO, Medline, Google Scholar, CINAHL and the Simon Fraser University library catalogue. A total of 69 articles that addressed the research questions were identified and incorporated in this review. Empirical evidence indicates that implementing person-centered care practices that honor the dignity and choice of residents, strengthen resident and care staff relationships and utilize nonpharmacological care to preserve the personhood of residents can improve the caring experience. In addition, there is evidence that person-centered care can improve the well-being and quality of life of residents and improve job satisfaction for care providers. This paper also examines the organizational facilitators such as the culture change, staff training and management's role, and environmental design as well as the organizational barriers in implementing person-centered care.

Keywords: person-centered care; relationship-centered care; long-term care; nonpharmacological care, culture change, barriers

*To my husband Rahil,
for your unconditional love,
for your unwavering support,
for being my pillar of strength,
for your faith in my passion,
for your positivity,
for being you.*

This could not have been possible without you...

I love you.

Acknowledgements

I would like to express my most sincere gratitude to my senior supervisor Dr. Habib Chaudhury- thank you for your support and guidance throughout my graduate studies. Your compassion as a professor, your genuine desire for students' success and your wealth of knowledge is extraordinary. I am forever grateful to have had you as my supervisor and mentor.

I want to thank my supervisor Dr. Deborah O'Connor for your constructive feedback and thoughtful advice throughout this project and to Dr. Jeff Small, my external examiner, for your perspective and recommendations for this project.

I also want to express my sincere appreciation to Mr. Dan Levitt for teaching me invaluable life lessons. I am so grateful to have you as a mentor and friend as I pursue my passion in gerontology.

I also want to say a very big thank you to my family near and far for your continued support throughout my time at school: to my two sets of parents- for being great listeners and my well-wishers throughout this exciting (and sometimes turbulent) journey and to my brothers and sisters - for being excellent recipients of my enthusiasms and rants.

Most importantly, a special thank you to my little boy, Faiz for truly being by my side from the beginning of my graduate studies. I hope your head start in gerontology ignites the compassion and will needed to support the aging population to live with dignity and respect.

Lastly, I want to express my appreciation to all the people living with dementia, aging in place or in institutional care, for your perseverance and strong will to overcome the adversity and social stigma attached to the disease. It is my sincere hope and wish to contribute to the 'change' we all want to see.

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Chapter 1. Introduction and Purpose

1.1 Background

Recent population projection estimates in Canada suggest that for the first time, there are more persons aged 65 and over than children aged 0 to 14 (Statistics Canada, 2015). One in six Canadians (16.1%) are over the age of 65; this number is projected to increase to 20.1% by the year 2024 (StatsCan, 2015). The rise in the aging population and increased life expectancy has pushed the health care systems to deliver high quality care to older adults with cognitive, physical and mental decline living in Long Term Care (LTC) facilities (Viau-Guay, Bellemare, Feillou, Trudel, Desrosiers & Robitaille, 2013). Long term care (LTC) refers to a range of medical, social and personal services to individuals who require day-to-day assistance due to chronic illnesses and/or physical impairments (Noelkar & Harel, 2001). In Canada, 5% of older adults over 65 years of age receive long-term care, with almost 30% of older adults aged 85 and over living in special, long term care facilities (StatsCan, 2012). The term 'long-term care' has inconsistent meanings - it often refers to long-term care provided in residential care facilities or extended care within hospitals, homes and communities (Alexander, 2002). For the purpose of this study, "long-term care" will be specific to care provided in residential care facilities.

Statistics indicate that over 60% of older adults living in long-term care facilities in Canada and the United States have some form of dementia (Hirdes, Mitchell, Maxwell & White, 2011; Thies & Bleiler, 2013). Dementia is a debilitating illness previously "characterized by multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning" (American Psychiatric Association, 2000, p. 148). In 2013, the American Psychiatric Association replaced the term dementia with "major neurocognitive disorder" (Diagnostic and Statistical Manual of Mental Disorders, 2013). The previous definition of dementia required memory impairment to be present for all dementias (Siberski, 2012), however, the new terminology recognizes that a neurocognitive disorder can be diagnosed even if memory impairment is not the first to be affected and if other areas of cognitive function including but not limited to aphasia, apraxia, agnosia are impaired (Diagnostic and Statistical Manual of Mental Disorders, 2013). The new terminology focuses on neurocognitive and functional changes to 'decline from previous level' as opposed to being 'deficit' (Siberski, 2012). It is alleged that the term

'dementia' has been replaced due to its stigmatization towards older adults and its denunciation amongst the younger population with HIV dementia (Siberski, 2012). Nonetheless, it is imperative to note that the term dementia has not yet been replaced in academic and grey literature and will therefore be used as is in this study.

People with dementia in long-term care have complex needs that include the need for social support, engagement in meaningful activities, 'behavior management' as well as the fundamental need for adequate food, proper accommodation and pain reduction (Reed & Tilly, 2008). It is important to understand, respect and reciprocate to these needs to reduce "disruptive behaviors" and increase quality of life for the residents (Kolonowski, Litaker, Buettner, Moeller & Costa, 2011; Kovach, Kelber, Simpson & Wells, 2006). Nazarko (2009) notes that only about 10% of residents' behavior is triggered by dementia itself, while 90% of it is a result of the quality of care received by people with dementia.

With the growing incidence of dementia, the World Health Organization and the Alzheimer's Disease International (2012) have also emphasized the necessity to improve the quality of care and services offered to people with dementia in care facilities (Willemse, Downs, Arnold, Smit, de Lange & Pot, 2015). Fazio and colleagues (1999) recommend care providers to make provision to identify and meet the needs and expectations of people with dementia. People with dementia express their core values and desires in many ways; these values should be incorporated in the basic philosophy of care of organization, providing services that enable these individuals to contribute and connect to the world around them (Bown et al., 2015; Fazio, Seman & Stensell, 1999). National dementia strategies suggest utilizing person-centered approaches to care for people with dementia, to mitigate the current gaps in care practices and dementia care organizations (Fortinsky & Downs, 2014; Pot & Petrea, 2013; World Health Organization and Alzheimer Disease International, 2012), further improving the quality of life of these individuals.

The past two decades have led to an idea of transforming care for older adults in LTC from a task-oriented to a person-centered care approach (Savundrayanagam, 2012). Kitwood and Bredin pioneered the idea of person-centered care in the late 1980s and 1990s, based on a "humanistic" concept, which accounted for the psycho-social aspects of care along with the widely practiced pharmacological care (Kitwood, 1997). The goal of this care approach is to acknowledge the *personhood* and individuality of the person being cared for especially the personalized needs of those with dementia (Downs, 2013; Viau-Guay et al., 2013). As this care

concept is not limited to or beneficial just for people with dementia, it has been widely implemented in multiple health care streams, especially long-term care facilities (Downs, 2013). Research indicates that facilities that offer a more flexible type of care promoting socialization, choice, autonomy and independence positively impact the quality of life of its residents as well as increase job satisfaction amongst staff (Norton, 2010; The Conference Board of Canada, 2011). While the supporting organizations may vary in the implementation of this type of care, the unanimous goal is to convert the hospital type impassive care provided at residential care to model a home-like person-centered environment that considers the needs and preferences of its residents (Weiner & Ronch, 2003).

1.2 Purpose of the Capstone Project

Considering the immediate need for reform and non-medicalization of care provided in long-term care facilities, this capstone project aims to review and synthesize current literature through a person-centered lens, with a focus on care practices and organizational issues. Long-term care facilities have typically been guided by the biomedical lens with the principles of pharmacological care being the primary intervention. Dementia care typically focuses on the abnormalities and functional challenges of the body organs due to the “disease” (Fazio et al., 1999). This biomedical view of care places all social challenges experienced by people with dementia as medical problems (Lyman, 1989), affecting the type of care received. Moreover, care providers often focus on providing a service as identified by professionals, with less emphasis on delivery of services that meet the gaps identified by the care recipients (Bown, Sanderson, & Bailey, 2015). By incorporating a person’s history, past, present and future goals, relationships, and the person’s needs and choices, care providers can provide responsive care that empowers individuals to have a better quality of life (Bown et al., 2015).

In the past decade, the long-term care industry has acknowledged the re-evaluation and transformation of ‘nursing homes’ to embrace older adults’ autonomy and independence, thus giving rise to a culture change movement (Koren, 2010). “Culture change” refers to the national movement of transforming older adult services to a person-centered care approach (Brune, 2011). The goal of culture change in long-term care is to modify policies, practices, values and beliefs to provide the residents with more respect, autonomy and choices throughout the day, as well as empower front line staff to provide optimum care (Jones, 2011). Typically, the ‘ideal facility’ that immerses in the culture change movement endorses resident-centered care, a homelike atmosphere, close relationships amongst residents, staff and family members,

collective decision making, team building and staff empowerment and ongoing quality of care and support to its residents (Jones, 2011; Koren, 2010).

Despite the manifold benefits of person-centered care, national dementia experts have identified several deterrents that limit the implementation of person-centered care principles and skills in care delivery (Love & Pinkowitz, 2013). For example, an inadvertent focus on finding a cure for dementia supersedes the urgent need to promote appropriate care for people with dementia (Love & Pinkowitz, 2013). Moreover, the overuse of antipsychotic drugs to control behavioral symptoms in people with dementia and lack of awareness for alternative forms of care necessitate a culture change from a biomedical approach to person-centered care (Love & Pinkowitz, 2013; Tellis-Nayak, 2007). Even with the organizations' will and determination towards a person-centered care approach, structural, environmental and financial barriers often impede the implementation of this practice (Rockwell, 2012).

Although person-centered care highlights the role of autonomy and resident choices, Lloyd (2004) asserts the importance of relationships in later life, claiming "the needs of older people at the end of life should be considered, not only in relation to their individual rights and claims but also in relation to their connectedness with others" (Lloyd, 2004, p.247), placing heavy responsibility on the camaraderie shared by care providers and receivers. Relational care or relationship-focused care extends from the person-centered care philosophy to an implementation model that specifies problem-solving practices and techniques in providing care that places importance on staff-resident relationships (Rockwell, 2012). This type of care explicitly focuses on direct care providers' relational skills and their quality of communication with residents, influencing the quality of life of long term care residents (Bowers, Nolet, Roberts & Esmond, 2007; Doty, Koren & Sturla., 2007; McGilton, Sidani, Boscart, Guruge, & Brown, 2012). The role of relational care is not of one to undermine the value of person-centered care practices; instead it is a response to the often-cited structural, environmental and financial barriers in the implementation of person-centered care. Relational care promotes direct care workers to utilize their skills to support residents in building meaningful relationships with staff, family and the extended community- at no extra cost- to fulfill their psycho-social needs (Rockwell, 2012). While the main focus of this study is to review person-centered care practices, fundamentals of relational care and its prospects of implementation in long term care facilities will also be briefly discussed.

A novel outcome of this project will be a consolidated review that includes conceptual literature and tenets of person-centered care and relational care that challenge the biomedical care approach. The review focuses on evidence-based person-centered care practices and organizational facilitators and barriers of implementing person-centered care in long term care facilities. This discussion will enable policy makers as well as key stakeholders of long-term care dwellings to identify and address challenges, and endorse care practices that are thoughtful and cognizant to the requests and wishes of the residents. This literature review will contribute to the existing discussion on person-centered care by documenting care practices and discussing organizational values that promote aging with dignity and optimize quality of life of long-term care residents. The goal of this capstone project is to produce a coherent document supported by theoretical literature and empirical evidence, which verifies the urgent need for culture change in long term care, which could be considered by care providing organizations to implement this change.

This chapter introduces the reader to the growing need for person-centered care practices in residential care facilities in efforts to improved quality of life of the aging population. Chapter 2 will review the methods used in conducting this review of the literature. Chapter 3 will be divided into three main sections; the first section will review and synthesize theoretical literature on person-centered care and relational care; the second section will discuss evidence-based and descriptive literature on person-centered care practices; and the final section of the findings will examine the organizational facilitators and barriers in implementing person-centered care in long term care facilities. Subsequent chapters will present a conceptual framework, deliberate over the findings and provide future research direction and conclusion.

The literature review is guided by two research questions:

- What is the evidence on person-centered care practices in long term care facilities?
- What are the organizational facilitators/barriers for implementing person-centered care and relational care?

Chapter 2. Research Method

An extensive literature review was conducted pertinent to the research topic and questions. This review aims to provide a concise description of evidence-based and replicable care practices and organizational values that promote person-centered care practices in their facilities. This thorough review of theoretical perspectives, empirical and non-empirical work and gaps in the current literature will enable “decision support” for policy makers, as well as leadership in the field of long term care and caring for people with dementia (Mays, Pope and Popay, 2005), with the goal to improve the quality of life of those living in long-term care facilities.

Several research techniques were utilized to identify relevant articles for the literature review. A key word search was conducted using the following databases: Ageline, PsychINFO, Medline, CINAHL, Google Scholar, and the Simon Fraser University library catalogue. The search keywords included *person-centered care, personhood, older adult(s)/aged, long-term care, nursing home, residents, people with dementia, relational care, relationship-based care, patient-centered care, resident-directed care, care practices, reminiscence, music therapy, communication, multisensory therapy, organizational culture, culture change, barriers, implementation, Green House project, Eden Alternative, dementia care, job satisfaction, staff perception, quality of life*. A search criteria was employed for efficiency and the key terms were used in various combinations. Due to the overlapping terminologies that define “person-centered care”, all journal articles that addressed person-centered care, care for people with dementia, relational care or non-medicalized care were reviewed. The guiding research questions helped control the scope of the literature reviewed. Initial search yielded 112+ results. Titles and abstracts were screened for relevant articles. Reference lists of selected articles were also reviewed for potential resources. Finally, articles that addressed the research questions outlined for this review were included. For the purpose of this literature review, 69 items (37 empirical; 32 non-empirical) were identified and incorporated in the systematic review.

The inclusion criteria for studies included in this review paper are: (1) items published in English, (2) published after 1990 (with the exception of conceptual literature), (3) empirical and non-empirical articles had to include person-centered care or person-centered care for people with dementia in LTC. Articles were excluded if they were not in English language and also if

they did not explicitly mention the terminologies: person-centered care, person-directed care, relational care, resident-directed care, patient-centered care.

Key articles were compiled in a tabular format as annotated summary of findings (Appendix A) for ease of reference, data collection and analysis. Both empirical and non-empirical were included in this summary. Empirical articles are referred to those sources that are evidence-based through quantitative or qualitative research on the given topic. Non-empirical resources include theoretical and conceptual frameworks, books, grey literature and websites. An example of the summary of findings table for all empirical and non-empirical articles regarding person-centered care or relational care is illustrated below.

Table 1 Annotated Summary Review Table - Example

Reference	List of authors of the study in APA style
Title	The search title of the study in APA style
Focus of Study	Briefly highlights the main purpose of the study or report
Methods	Indicates the research design and sample information; quantitative, qualitative, interviews, case study, questionnaire, etc.
Key findings	Summary of the main results, outcomes and key points of the study relevant to the research questions and topic of this review
Limitations	Any short comings in the research implementation and study findings identified by the author/s
Relevant to PCC/RC	Points if the article discusses person-centered care or relational care

The rigorous research method was utilized for precision and effective management of data. The research questions serve to guide the research and acquire relevant data for this extensive literature review. The inclusion and exclusion criteria assist to control the scope of the literature and its relevance to the given topic. The annotated summary table gives the reader a chance to view all included articles and understand its importance in the overall findings and discussion of this capstone project.

Chapter 3. Literature Review

The following sections will review empirical and non-empirical materials on person-centered care practices in long-term care facilities. The review is divided into three main sections --- theoretical literature on PCC, empirically based person-centered care practices in LTC, and organizational facilitators and barriers in the implementation of PCC in long term care. A total of 69 articles were reviewed; 37 empirical and 32 non-empirical articles. A detailed summary of the included articles can be found in Appendix A

3.1 Theoretical Literature on Person-Centered Care

The concept of person-centered care for people with dementia, offers an alternative to the traditional medical model of care (Downs, 2013; Kitwood, 1997; Zhong & Lou, 2013). This review is an attempt to critique and expand upon the conventional interpretation of dementia, that is rooted in the biological aspects of dementia as a disease and the shortfalls associated with the neurodegenerative changes (Stein-Parbury, Jeon, Brodaty & Haas, 2012). The following sections will briefly deliberate the understanding of dementia through a biomedical lens, which will be challenged by the person-centered lens of understanding the ‘disease’. Subsequent sections will examine the socially constructed definition of personhood that contests the biomedical understanding of the many symptoms associated with dementia. The importance of person-centered care and its role in how the person with dementia is understood and treated in their environment will also be discussed

3.1.1 Key concepts in person-centered care

3.1.1.1 *Dementia and its care*

The biomedical approach assumes that dementia is an outcome of brain damage and the “symptoms of dementia” are a result of the neuropathology as the disease progresses (Sabat, 2008). Once known as a “rare” disease, dementia is known to have life changing consequences for the recipient as well as their caregivers (Borbasi, Jones, Lockwood, & Emden, 2006). The condition is known to impact social, emotional, functional as well as cognitive ability to reason and comprehend, impairing the performance of instrumental activities of daily living (IADLs) such as activities like food preparation and grocery shopping (Lawton &

Brody, 1969). It also impacts routine activities of daily living (ADLs) such as self-care and feeding (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963).

Extensive research on Alzheimer's Disease- a common type of dementia- presents multiple behavioural and cognitive changes in the functioning of those affected. Ordinary tasks like the ability to drive, find and pronounce the appropriate words in conversations, recollect recent events, write, manoeuvre equipment or complex tools, maintain focus and attention, and ultimately to even eat, deteriorate (Sabat, 2002). Reisberg and colleagues (1987) also attribute changes in personality and psychiatric symptoms like hallucinations and delusions as possible outcomes of this disease. As the dementia progresses, complex tasks like telephoning, finance management and adherence to medication may also be a challenge for people with the condition (Peres, Helmer, Amieva, Orgogaza, Rouch, Dartigues, & Barberger-Gateau, 2008), compromising the safety of older adults with dementia to age in place.

The biomedical lens perceives behavioural and psychological symptoms of dementia (BPSD) such as agitation, aggression and anxiety as common by-product of the disease (Sabat, 2008) and practices behaviour management techniques to alleviate 'suffering' and distress amongst the residents. It is no secret that long-term care facilities often resort to psychotropic (psychoactive) medication, especially antipsychotic drugs to doctor aggressive behaviours amongst residents (Ballard, Waite & Birks, 2012; Rolland, Andrieu, Crochard, Goni, Hein & Vellas, 2012). While this short-term treatment yields temporary results, its effect on long-term therapy is questionable (Ballard, Corbett, Chitromohan & Aarsland, 2009). Despite the adversarial effects of antipsychotic drugs namely decreased quality of life, faster cognitive decline, and traumatic stroke or death, its practice is widespread (Ballard et al., 2009; Brown et al., 2012). Evidently, long-term care facilities that foster people with dementia collect twice as many prescriptive antipsychotic drugs than those without dementia (Rolland et al., 2012). Critics claim that these drugs "only aim to dampen the activity without considering the care" (Melin & Olsen, 2006, p. 115)

For decades, a biomedical phenomenon has dominated the understanding of dementia as a neuropathological, and irreversible disease (O'Connor et al., 2007; Sabat, 2008). However, a person-centered lens challenges the notion of a strictly biomedical approach, with research to show that behaviours of people with dementia are affected by at least four different factors (Harris, 2002; Killick & Allan, 2001; Sabat, 2001; Synder, 1999; Wilkinson, 2002):

- brain damage
- the person's reaction to the effects of the brain damage
- the ways in which the person is treated by healthy others
- the reactions of the diagnosed person to the ways in which he or she is treated by others

(Sabat, 2008, p. 71).

According to Kitwood (1997), the experience of dementia can be most usefully understood as a 'socially embedded experience', and a result of complex interactions between the person's neuropathic part of the brain, life history, health status, social environment and "malignant social psychology" (Davies & Nolan, 2008; Kitwood, 1997). Malignant social processes, namely acts of infantilization, disempowerment or objectification by caregivers towards people with dementia, diminish their personhood and deprive them from their humanity (Barbosa et al., 2014; Kitwood, 1997; Sabat, 2008). Care providers often assume dementia to be accompanied by loss of selfhood, resulting in care that treats persons with dementia as "objects" rather than "persons with dignity and respect" (Kitwood, 1997). Negative care practices such as ignorance of essential needs of residents, demands exceeding the person's cognitive and physical capacity, mistreatment, and harsh communication can cause disruptive behaviours amongst people with dementia (Stein-Parbury, Chenoweth, Jeon, Brodaty & Haas, 2012). Therefore, it can be argued that many of the "difficulties" experienced by people with dementia are not caused directly by the disease itself, but instead manifested by the social environment created for them (Davies & Nolan, 2008; Kitwood, 1997), and that the person with dementia simply responds to being treated as a 'non-person'.

Advocates of person-centered care, consistently reiterate agitation and other behavioural symptoms in people with dementia to be reactions of unmet bio-psychosocial needs and necessitate care practices geared to compensate for these disparities. For better understanding it is critical to differentiate between behaviours that are symptoms of neuropathology or bluntly, an emotional reaction to "dysfunctional social treatment" by 'healthy others' (Sabat, 2008). This person-centered conceptualization offers an optimistic resolution to the 'behavioural symptoms' of dementia and indicates that some of the negative consequences of the disease can be alleviated by attending to the *individual personhood* of people with dementia to positively influence their experience (O'Connor et al., 2007).

3.1.1.2 The “person” and “personhood”

The word “person” broadly defines the individual characteristics of being human and the factors attributed to the important and challenging facets in a human’s life (McCormack, 2004). Frankfurt (1989) describes this ability of self-reflection and evaluation of one’s purpose as ‘second order desires’ or ‘desires of the second order’. From a gerontological perspective, the idea of *second-order reflection* supports the understanding that individuals in later years make life decisions based on their guiding principles and preferences for a life they desire (McCormack, 2004). These individual reflections also influence an older adult’s adaptation to change, engagement in the community or being alone, the maintenance of relationships, and the response to situations (McCormack, 2004).

Often in later life, an individual is ripped off the gains of being a ‘person’ and constricted from making their own decisions (McCormack, 2004). Even though a person may no longer be able to convert their choices and desires to actions due to-for example- impairment, they always have the freedom to think, feel and embrace desires like nothing has changed (Frankfurt, 1989; Berlin, 1992; McCormack, 2004). McCormack (2004) explains the universal moral obligation of humankind to provide all persons with the status of humanity, dignity, value and ‘irreplaceable worth’ protecting their *personhood*, despite their level of ability or competence. In his plea to honor dignity and self-esteem, McCormack (2004) reiterates the value of respect and the mere disgrace in objectifying persons to “things” in later life. As implied by Immanuel Kant, “persons should always be treated as ends in themselves and not as a means to another’s end” (translated by Sullivan (1990) in McCormack, 2004). Yet certain situations limit the practice of this morality and compromise individual quality of life due to medical, financial and managerial gains (McCormack, 2004). For example, large nursing homes historically succumb to rigid care practices based on organizational needs, and compromise the needs and treatment of its older residents (Goffman, 1961; Norton, McLaren, & Exton-Smith, 1976).

The term *personhood* is defined by the multiple traits that make up a “person” or culminates the existence of a human being (Burton, 2008). The pioneer of person-centered care, Tom Kitwood (1997) describes *personhood* as “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.08). Kitwood (1997) highlights personhood 1) as a relational concept- one does not ‘possess’ personhood but instead it is established in the way a person is treated by others; 2) as being dynamic; 3) in a situational context- i.e. the social and

physical environment can either support or challenge personhood; and 4) a unique, individual encounter between two people (Baldwin, 2008, p. 106). According to Kitwood (1997), a person's personhood is not threatened by the diagnosis or progress of dementia, but instead undermined by the individual and society's responses to the disease (Baldwin, 2008). Subjectively, a person's status of "personhood" develops overtime from its conceptualization in a mother's womb to its conclusion at the end of life (Buron, 2008). Age, societal influence, cognitive and physical competence are all contributing factors in the development of personhood throughout an individual's life course (Buron, 2008).

Sabat & Harre (1992) and Sabat (2006) do not explicitly discuss personhood, but use the concepts of social construction theory in the analysis of selfhood as applied to individuals with moderate to severe dementia (Nowell, Thornton, & Simpson, 2011). The notion of social constructionism posits that people with dementia 'co-construct and define themselves' through their social interactions and encounters (Hughes, Louw, & Sabat, 2006). This means that 'behaviors' of dementia are not purely a result of the disease, but an outcome of the socially constructed positioning of people with dementia by the others (Sabat & Harre, 1992; Sabat, 2006). Socially constructed theories of dementia are not based on objective knowledge, but instead developed from the views and meanings people ascribe to the situation (Synder, 2006). Much of the stigma and propagations of 'tragic dementia' is socially constructed as 'the loss of self', 'empty shell', and the possibility of a 'long goodbye' (Synder, 2006). Undoubtedly, at the onset of disease, people with dementia are subject to prejudiced communication and interaction in their social environments, which diminishes their selfhood or personhood (Synder, 2006).

Sabat's (2002) Selves 1-3 constructs describe the public discourse encountered during the journey of dementia for the affected. Self 1 is the expression of an individual's feelings and experiences using first-person indexicals such as "I", "me" through verbal and non-verbal communication (Kelly, 2014). Sabat (2002) states that much of Self 1 remains undamaged in people with dementia. Self 2 is made up of physical, mental or emotional characteristics and one's perception of these attributes. Again, Sabat (2002) argues that a person with dementia is intact with these attributes despite cognitive decline, but may be vulnerable when difficulties associated with the neurological state of dementia are directly blamed to the person's ability. Sabat (2002) posits Self 3 is made of "various different social personae which we construct in the variety of situations in which we live our lives". Self 3 is socially constructed and can change through the interactions with the "healthy" and is therefore more susceptible to damage than

Self 1-2 (Kelly, 2014). Sabat's work is useful for care staff as they recognize commonalities of selfhood with people with dementia while delivering care (Kelly, 2014).

Contrary to Kitwood (1997) and Sabat (2006), Buron (2008) outlines a structured perspective on personhood through three distinct levels (Nowell et al., 2011). The first level *biological personhood* indicates that the biological existence of a person is in itself a fundamental attribute of personhood (Coker, 1998; Donovan, 1983; Harrison, 1993). It reflects in the individual's ability to experience gratification and pain (Moody, 2003). Since persons with dementia are able to retain these features, the first level of the personhood status is unquestionably maintained for them (Buron, 2008).

The second level of personhood i.e. the *individual personhood* is often defined as a culmination of various traits like a person's past, personality, values, roles, self-worth, emotional stability, affection etc. developed along the life course (Coker, 1998; Gillett, 2002; Harrison, 1993; Touhy, 2004). Self-awareness (i.e. the identification of ones past to present) and the capability to communicate are two distinct features that define the second level of personhood (Harrison, 1993; Jenkins & Price, 1996; Moody, 2003; Perry & O'Connor, 2002; Pullman, 1999). People with dementia are often deprived of their individual personhood due to several distressing factors. First, cognitive functioning worsens as the disease advances; this challenges the individual's ability to reason, rationale and connect life events, categorizing them as someone who has changed or just a "non-person"-jeopardizing their individual personhood (Buron, 2008; Chan, 2004; Doyal & Wilsher, 1994). Second, with the progression of the disease, persons with dementia gradually lose their capacity to communicate; this limits the caregiver's ability to learn about the person's past, personality, and individual personhood (Buron, 2008). These changes are exacerbated by high staff turnover in organizations and conventional methods of care where caregivers are focused on providing biomedical care to meet the needs of the physical being (Buron, 2008).

The third level of personhood, *sociological personhood* is outsourced to society's perception of the individuals and the subsequent interactions that follow (Cecchin, 2001; Davis, 2004; Malloy & Hadjistavropoulos, 2004; Perry & O'Connor, 2002). People's perceptions of others may alter as a consequence of significant changes in a person's life. For instance, perceptions of someone's social status may be lost if they are diagnosed with dementia (Palmer, 2013). A person's status is determined by the frequency of social contacts, membership in the community, relationships, "moral agency" in the society (Cecchin, 2004;

Dombeck, 1997; Harrison, 1993); how people with dementia are treated in these roles notably depend on the society's perception of the disease. Communicative irregularities like repetition, inconsistency in thought, and forgetfulness of appropriate words may begin to deteriorate in the early stages of dementia, making individuals more susceptible to societal judgment and isolation (Buron, 2008). With the progression of the disease, individuals with dementia may have challenges mobilizing through their environment; "being slow", "being lost", and "being blank" are irrepressible attributes that threaten their sociological personhood (Buron, 2008; Phinney & Chesla, 2003). Moreover, older adults living with dementia in long term care facilities may also be socially isolated and not encounter many opportunities for socialization or relationship building with the advancement of the disease (Buron, 2008).

Given the risks, institutional environments are placed with a moral responsibility to preserve and maintain the levels of personhood for residents with dementia. Understanding and maintaining personhood is critical in the care of individuals living with dementia (Kelson, 2006; Kitwood, 2007) and is closely linked to delivering person-centered dementia care (Nowell et al., 2011). Studies indicate that preserved personhood amongst persons with dementia improves their physical and mental wellbeing and enriches the quality of care when residents are unable to express themselves verbally (Cecchin, 2004; Harrison, 1993). Failure to preserve personhood for residents with dementia results in "depersonalization", higher rates of depression, social isolation, loneliness and a loss of self (Buron, 2008; Coker, 1998).

Although the concept of personhood is critically recognized in dementia care literature as an advocate for preserving the self of people with dementia, it has some limitations (Barlett & O'Connor, 2007). Barlett & O'Connor (2007) contend that personhood endorses an individualized lens of positioning the dementia experience at a personal level, rather than placing it at a social and political level that extends beyond the individual and his or her immediate environment. This quandary limits dementia care research to a micro level without much emphasis on the impact of such experiences at a more macro level to understand the greater social struggles that influence the experience of living with dementia (Barlett & O'Connor, 2007). Moreover, while the personhood lens promotes the intrinsic value of the person with dementia, its conceptualization as a status bestowed by others, inertly positions the person with dementia to be reliant on others for support and recognition (Barlett & O'Connor, 2007). Furthermore, personhood is 'apolitical' that is, it primarily focuses on the psychological and health (psychosocial) matters without discussing people's situations in terms of power and control (Barlett & O'Connor, 2007). Consequently, socio-political matters such as discrimination,

stigma, and engagement in politically driven activities could possibly be overlooked or disregarded in the lived experiences of people with dementia (Barlett & O'Connor, 2007).

3.1.1.3 Person-Centered Care

Person-centered care was originally the work of Carl Rogers and *client-centered psychotherapy* in the 1960s (Brooker, 2007). Rogers advocated for change in the biomedical model of care, with greater emphasis directed to the strengths and desires of individuals with illnesses and less on the task of caregiving (Barbosa, Sousa, Nolan & Figueiredo, 2014; Rogers, 1961). Rogers' thinking has greatly influenced the interpretation and facilitation of therapeutic relationships and emotional instabilities amongst people with dementia (Brooker, 2007; Morton, 1999).

This notion of care was further developed by Tom Kitwood specifically to meet the behavioural and psychosocial needs of people with dementia (Barbosa et al., 2014). Person-centered care centers around the 'whole person' (not just dementia) and focuses on the retained abilities of the person in relation to their family, preferences, culture and society (Cheston & Bender, 1999). One of the key principles of person-centered care support the idea that behaviours in people with dementia are a result of the quality of care received and a sign of unmet need (Brooker, 2007; Kovach, Noonan, Schlidt, & Wells, 2006). Kitwood's model of care advocates for human relationships to maintain 'personhood' and person centered care approaches that meet six psychological needs of care recipients: "love; attachment; comfort; identity; occupation; and inclusion" (Kitwood, 1997). Person-centered care emphasizes focus on life history, experiences, values and individual preferences of older adults (Kitwood, 1997). It goes beyond delivering individualized care as it encourages health care systems to provide love, affection, comfort and attention that enhances a person's sense of self and value, retained strengths and abilities and focuses on well-being (Stein-Parbury et al., 2012).

PCC promotes "an interpersonal theory of care" where care staff understands their role in preserving the personhood and maintaining the well-being of persons with dementia (Davis, 2004; Stein-Parbury et al., 2012). Kitwood's (1997) philosophy of care is interdependent in nature where the carer or caregiver is valued equal to the care recipient. Kitwood (1997) asserts that a person-centered care practice is not possible unless staff also experience a 'staff-centered work environment'. For the successful implementation of a person-centered care model, caregivers require adequate training and support from the management, independent decision making opportunities, necessary input and resources, respect and recognition of

emotional strains, meaningful interactions and a positive working experience (Barbosa et al., 2014; Stein-Parbury et al. 2012)

Person-centered care is an alternative to the traditional biomedical model of acute care in long term care facilities that classifies residents with dementia as diseased, leaving them alone for long hours and emotionally distressed (Chenoweth et al., 2009) Long-term care facilities that choose to transform care from a medical model to a more person-centered approach provide interactional social environments that improve quality of life of residents and quality of care provided by staff (Norton, 2010). Person-centered care shifts focus of care from disease to illness and from objective medical needs to the subjective well-being of the person (Edvardsson, Fetherstonhaugh, McAuliffe, Nay and Chenco, 2011). Most importantly, this care model progresses from the basic fulfillment of biological personhood to a more holistic approach that meets all aspects of personhood. Person-centered care thrives on the belief that positive and enriching interpersonal relationships outweigh the negative, debilitating losses that occur with dementia (Brooker, 2003; Davis, 2004; Dewing, 2008). Studies indicate many benefits of person-centered care on quality of life outcomes on residents such as decreased use of antipsychotic medication (Fossey, 2006), decreased behaviours such as aggression and agitation (Chenoweth et al., 2009; Sloane et al., 2004), and increased social participation (Sidani, Streiner & Leclerc, 2012).

Kitwood (1997) suggests the inclusion of a person's medical as well as social and functional histories to enable care environments to acknowledge the individual's remaining strengths and abilities in place of losses and deficits (Stein-Parbury et al., 2012). Individualized care plans built on person's life history, desires, choices and preferences allow care staff to deliver customized and sensitive care to persons with dementia and respond to their needs accordingly (Stein-Parbury et al., 2012).

Person-centered care is often synonymous to the terms family-centered, patient-centered, user-centered, client-centered, individualized or personalized care (McGilton et al., 2012; Nandini, Sridhar, Usharani, Kumar & Salins, 2011). While all these terms convey the same idea that the care directed takes into account the individual's needs, preferences, choices, behaviors, feelings, and perceptions (Radwin & Alster, 2002; Suhonen, Valimaki, & Katajisto (2000); Suhonen, Schmidt, & Radwin, 2007), it can be argued that the term 'patient-centered care' is inherently problematic to describe this type of care as it is solidly grounded within a biomedical lens, in that the person is already lost as a 'patient'.

The complex concepts of person-centered care make it difficult to develop a concrete definition for its operators (Brooker, 2007). In the absence of a universal meaning, person centered care has been used duly by care providers, practitioners, researchers, people with dementia and families, to mean different things in different situations, amongst different people (Brooker, 2007). Oftentimes, person-centered care is described as core values and beliefs that the 'person' remains irrespective of the diagnosis of dementia, in providing care unaccompanied by set guidelines for implementation (Brooker, 2007; Rockwell, 2012). Some explain PCC as synonymous to individualized care while others regard it as a useful set of guidelines and techniques of care practices for enhanced care (Brooker, 2007). In some instances, the phenomenological perspectives of person-centered care are grounds for better care and means for direct communication with individuals (Brooker, 2007).

Brooker (2004) reviewed the work of Kitwood and other existing literature on PCC and identified four essential elements to provide a contemporary definition of person-centered care approach:

PCC (Person-centered care) = *VIPS*

V (Values) + I (Individualized) + P (Perspective) + S (Social Environment)

While each of the above elements is noted to exist independently, collectively they define a "powerful culture of a person-centered approach to care" (Brooker, 2007). Brooker (2007) explains each of the contributing elements in her definition in much detail:

Valuing people with dementia and those who care for them (V)

Carl Rogers' (1961) perspective values the uniqueness of individuals and advocates for unbiased, therapeutic and optimistic care. In an attempt to deliver unconditional treatment to people with dementia, the *definition of person* is critical (Brooker, 2007). Alternatively, Hughes (2001) definition of a person as "situated-embodied-agent" calls on unconditional treatment of people with dementia in a way all people would like to be regarded. Similarly, Kitwood and Bredin's (1992) description of a person with dementia as "a person in the fullest sense" also seeks to value these individuals nonjudgmentally.

Person-centered care thrives to value all individuals unanimously despite their mental capacity (Brooker, 2007; Post, 1995). However, a glimpse into the service industry reveals that people with dementia are not valued and often victims of prejudice (Ballard et al., 2001;

Brooker, 2007; Innes & Surr, 2001; MacDonald & Dening, 2002; Marshall, 2001). The society's preference for youth, intellect and consciousness inadvertently discriminates against the aged and particularly those with cognitive impairment- this type of special ageism is referred as *hyper-cognitivism* (Post, 1995). According to Brooker (2007), "dementia-ism"- a better-suited term to expose the victims of this special prejudice i.e. people with dementia- is manifested in service provisions, research funding, allocation of resources, media depiction as well as in policy preferences and professional settings. To nourish person-centered care approach in services, it is essential the PCC definition proactively eliminate "dementia-ism" and value personhood, inclusion and unconditional regard for people with dementia (Brooker, 2007).

Treating people as Individuals (I)

The core essence of person-centered care lies in the ideology of treating people as unique beings. PCC exemplifies a customized approach to dementia care that treats the incapacitating disease as part of a person's existence and not the definition of their identity (Brooker, 2007). The varied definitions of person-centered care unanimously stress on the significance of individualism. Claire and colleagues (2003) highlight the importance of personalities, life histories and social identities as contributing livelihood factors for people with dementia. Archibald (2003) describes person-centered care to be a way for people with dementia to navigate through their different experiences of the disease and to receive the desired care. Marshall's (2001) view of person-centered care places the focus of care on the person with dementia, as opposed to the needs of the staff or caregivers in delivering care (Brooker, 2007). Therefore person-centered care reiterates the importance of treating individual needs and providing tailor made services to benefit and improve the wellbeing of persons with dementia.

Looking at the world from the perspective of the person with dementia (P)

Brooker (2007) describes person-centered care to be rooted in the 'phenomenological school of psychology' placing importance to the subjective experiences of people with dementia, the behaviours triggered as part of that "reality" and therapeutic solutions for effective care. Based on Rogers (1961) ideology of therapeutic approaches, person-centered care necessitates seeing the world from the eyes of those with dementia and reciprocating with care that meet their needs (Brooker, 2007). Researchers hold high importance to the recognition and realization of the subjective experience of people with dementia in a psychosocial context as

key to individualized care approaches (Claire et al., 2003; Kitwood, 1997; Stokes, 2000). Without putting oneself in the shoes of people with dementia, care providers may limit their scope to deliver therapeutic and empathetic care (Brooker, 2007).

A positive social environment (S)

Person centered care promotes and nurtures interpersonal relationships between the care provider and the recipient (Brooker, 2007). Verbal communication diminishes with the progression of dementia, increasing the need for nonverbal human contact through acts and gestures to maintain the personhood of individuals (Brooker, 2007; Morton, 1999). The Rogerian view highlights relationships to be key to therapeutic care (Rogers, 1961). Kitwood (1997) also reiterates the importance of preserving personhood as grounds of person-centered care. In his writing, he states *recognition* and *trust* to be critical factors in building social relationships (Kitwood, 1997). Bond (2001) also explains that “human life is interconnected and interdependent” implying “individuals do not function in isolation”. Although nurturing interpersonal relationships for people with dementia seem like the logical common practice, many care providers fail to do so (Brooker, 2007). Low staffing, poor communication skills, unequipped organization structures and limited training of direct care workers are typical obstructions in a positive and nurturing environment for people with dementia (Brooker, 2007). Despite these obstacles, many dementia care practitioners use imagination and creativity to provide customized care (Packer, 2000; Trilsbach; 2002). Some examples of popular therapeutic care strategies for people with dementia include reminiscence, life-story work, pet therapy, doll therapy, music, multisensory therapy, psychotherapy etc. (Brooker, 2007). The culmination of positivity, communication and psychotherapeutic work in dementia care can preserve personhood as well as foster a positive social environment for people with dementia (Brooker, 2007).

3.1.2 Relational Care

Person-centered care provides a beneficial shift in the ideology of care for residents in long-term care facilities. While it emphasizes the worth of autonomy and independence for older adults, conferring a sense of authority and decision making in the hands of the residents in LTC (Rockwell, 2012), conflicting views imply that stressing on these traits essentially restrains the quality of care for the aging cohort (Lloyd, 2004). The superficial idea of independence and autonomy in old age stigmatize the frail, the physically challenged, or the cognitively declined and disregard the “necessity of interdependence at all ages” (Lloyd, 2004; Rockwell, 2012). Lloyd (2004) argues that the needs of older adults extend beyond their autonomy giving importance to relationships and connections with others who provide care. Other critics argue that autonomy is “incapable of underpinning any shared societal responsibility for the health of all its members, including the least advantaged” (Evans, 1999, p. 13) and unsustainable in the realms of care provision for older adults (McCormack, 2001).

Autonomy is not necessarily a feature of effective care; it is a prestige acquired in the life course of individuals through social interactions and the establishment of a sense of independence and purpose amidst the web of relationships (Nedelsky, 1989; Rockwell, 2012). Given this view, ideal care would be a juxtaposition of autonomous and inter-relational care that promotes a sense of belonging for the care recipient and provides opportunity for individuality and independence.

Although, PCC philosophy places the person in the center of the care milieu, critics of PCC protest its failure to recognize the significance of inter-personal relationships in care facilities (McCormack, 2012; Nolan, Davies & Grant, 2001). Limiting care to person-centered and individualistic needs fundamentally puts the ‘person’ in isolation and encourages one-sided care without return benefits to the caregiver (Rockwell, 2012). Furthermore, in the efforts to maintain personhood and independence of the person being cared for, PCC naively undermines the value of those providing care (Nolan et al., 2001). Brechin (1998) describes “good care” to be a by-product of the inter-relationship between the care provider and care receiver, and the identification of “fundamental similarities” in the relationship.

The term “relationship-centred care” or relational care emerged in the 1990s as a different approach to care focused on a combination of sociological, biological and psychological factors (Nolan, Grant, Keady & Lundh, 2003). This new model of health care

delivery focuses on “the importance of interactions amongst people as the foundation of any therapeutic or healing activity” (Tresolini et al., 1994, p. 22). Relationship-centered care approach supports ‘symmetry’ and ‘synchronicity’ as critical elements within the relationship (Nolan et al., 2003). The fundamental basis of this care approach is to recognize and value the contributions of all stakeholders (residents, care staff and families), and to incorporate each perspective within the caring relationship for the delivery of optimum care (Nolan et al., 2003). Nolan and colleagues (2003) identify the contributing factors vital to implement and sustain this positive caring relationship within care facilities- they coined this the ‘Senses Framework’ which they described as considering all aspects of care including the subjective experiences of the interpersonal relationships between the care giver and recipient (Davies et al., 1999; Nolan, 1997; Nolan et al., 2001, 2002). The framework extends the ideas of person-centered care, to incorporate the psychological needs of the older adults, families and care staff to create a set of senses and experiences (Davies & Nolan, 2008). These are:

- a sense of security: to feel safe while delivering and receiving sensitive care
- a sense of continuity: to use ‘biography’ as a means to connect the past to the present
- a sense of belonging: opportunities to build meaningful relationships and working in teams
- a sense of purpose: opportunities to engage in purposeful activities and have goals to aspire to
- a sense of achievement: to achieve valued goals and feel satisfied in the efforts/process
- a sense of significance: to feel valuable as a person (Nolan et al., 2006)

(Davies & Nolan, 2008, p. 444)

Based on the belief that all stakeholders (i.e. the older adult, family caregivers, paid and unpaid caregivers) that give and receive care benefit from this process, the Senses framework is designed to promote “security, belonging, continuity, purpose, achievement and significance” for all parties involved. The framework endorses ‘good care’ and most importantly a sense of satisfaction during the care process (Nolan et al., 2001). In doing so, the framework proves to be a rationale for effective care practices in institutional settings as well as acute hospital care for older adults (Davies et al., 1999; Nolan et al., 2001).

Relational care strives to improve the socio-emotional well-being of residents in care homes and their care-providers through direct care worker relationships, mentorship, networking and reaching out to the wider community (Rockwell, 2012). Essentially, relationship-centred care overcomes organizational barriers (for example, funding restrictions or staffing issues) by increasing the array of relational ties between staff and resident resulting in more meaningful activities and quality interactions (Rockwell, 2012). Based on loose guidelines, relational care offers therapeutic ways to build and support multidirectional relationships between staff, residents, family members and the social circle (Rockwell, 2012). The powerful inter-relationships enable staff to learn of resident backgrounds and interests and provide opportunities for valuable engagement ranging from mentorship to caretaking roles or social immersion (Rockwell, 2012). An important aspect of relational care recognizes resident ties to the wider community that extend socio-emotional care beyond the scope of a residential facility (Rockwell, 2012). Pre-existing social support from family, friends, neighbours and religious groups provide a sense of belonging for long-term care residents, preserve personhood and deliver care as per their needs (Rockwell, 2012).

3.2 Evidence-based Care Practices for Person-Centered Care

One of the key principles of person-centered care supports the idea that behaviours in people with dementia are a result of the quality of care received and a sign of unmet need (Brooker, 2007; Kovach et al., 2006). Thoughtful consideration and appropriate response to the needs of people with dementia are key to their improved quality of life and decreased negative behaviors (Kolanowski et al., 2011; Kovach et al., 2006). A plethora of studies focus on the occurrence of negative behaviours in people with dementia, however limited studies discuss the real needs of people with dementia in residential facilities (Cadieux, Garcia & Patrick, 2013). While the fundamental need of food and shelter are usually met at long term care facilities (Hancock et al., 2008), care practices should include pain management, social support, and opportunities for meaningful social engagement for the residents (Reed & Tilly, 2008). Older residents at LTC report lack of stimulating daytime activities, limited staff support during psychological distress and moderate help with memory, eyesight and hearing problems as unmet needs (Hancock, Woods, Challis & Orrell, 2006; Orrell, Hancock, Liyanage, Woods, Challis & Hoe, 2008). Cadieux and colleagues (2013) also identify LTC residents' ongoing desire for meaningful activities, personalized need for care and emotional need to preserve their personhood

Recognized needs of people with dementia necessitate proactive care practice strategies to promote a sense of belonging, acceptance and better health for residents in care facilities. Best care practices that advocate for person-centered care highlights *preserving personhood- honoring dignity and choice, importance of relationships and communication, and non-pharmacological care* as critical factors that protect the 'self' of older adults in LTC. This section of the capstone project will discuss care practices in LTC facilities supported by empirical research and its impact on the well-being of the residents.

3.2.1 Preserving Personhood- Honoring dignity and choice

Care practices that encourage residents' choice and power over everyday, non-dramatic events by incorporating life story, personal preferences and values, facilitate a good life for its residents (The Ministry of Social Welfare, 2013). Choice and autonomy over everyday activities increases satisfaction, promotes maintenance of meaningful activities and improves quality of life for older adults living in long-term care (Collopy, 1995; Duncan-Myers & Huebner, 2000; Kane, Lum, Cutler, Degenholtz & Yu, 2007). Approaches to care that involve residents in daily

chores such as folding laundry, assisting at mealtimes, or room cleaning stipulates purpose and sense of responsibility (Stein-Parbury et al., 2012).

Care providers commonly assume dementia to be accompanied by loss of selfhood resulting in care that treats persons with dementia as “objects” rather than “persons with dignity and respect” (Kitwood, 1997). This assumption is not limited to those with dementia, and often practiced when providing task-oriented care to older adults in LTC. In a study to examine the experiences of older adults’ choice and autonomy in a traditional model of LTC, residents felt their needs were not respected, unmet or delayed by care staff (Tuominen, Leino-Kilpi & Suhonen, 2014). In the same study, older adults claimed they had no opportunity to make decisions regarding frequency of meals, when to take showers, the use of toilets instead of the bedpan or incontinence pads and the provision of timely care when in need (Tuominen et al., 2014).

Essential activities such as waking, eating and going to sleep often depends on the availability of staff, rigid regulations of the facility, and require unconventional care practices and organizational efforts to facilitate *choice* for residents in this matter (Burack et al., 2012). Utilizing aspects of person-centered care practices in the organization, like knowledge of the preferences, needs and abilities of residents, encourages and promotes dwellers to execute activities of daily living (ADL) as independently as possible (Sjogren, Lindkvist, Sandman, Zingmark & Edvardsson, 2012). In a study to examine the relationship between person-centered care practices and the activity level, pain endurance, aggressive behaviours and quality of life of people with dementia, Sjoren and colleagues (2012) found a positive correlation between person-centered care practices and higher level of ADL ability such as toileting, eating and drinking. These findings indicate that person-centered care interventions such as choice and independence have a positive impact on residents’ quality of life; it increases resident involvement in ADLs and preserves functioning and independence (O’Connor, Smith, Nott, Lorang, & Mathews, 2011; Nazarko, 2009; Sidani et al., 2009; Sjoren et al., 2012).

Burack and colleagues (2012) studied the transformation of a medical model of care to a person-centered care approach in a long- term care facility and its effect on resident choice. Findings from the research show greater scope of resident choices in areas of leisure activities through person-centered care practices but little effect on choices regarding eating, bathing or sleeping. These results, once again reiterate that inflexibility of established routines and

inadequate human capital hinder the application of person-centered care in routine, fundamental activities of daily living (Burack et al., 2012).

The Eden Alternative, synonymous to person-centered care, promotes care practices that allow its residents to choose their mealtimes, bath times and wardrobes (Sampsell, 2003). This type of care approach increases self-care as residents' needs are prioritized over the facility's preferences (Sampsell, 2003). It aspires to foster care practices that incorporate residents' individual preferences to match the type of care needed, with no compromise to their need for privacy and autonomy. Resident and family engagement in developing person-centered care plans- as seen in the Eden Alternative-also prioritize needs of residents, respect their dignity and choice and optimize prospects of well-being for care receivers (Whitlatch, 2013).

Notably, care practices towards people with dementia often disregard the individual's moods, choices and behaviours due to their cognitive inabilities and debilitating responses - stripping them off their personhood (Palmer, 2013). In the comforts of their home, it is reported that family caregivers continue familiar routines and structured activities for family members living with dementia as a coping strategy and to maintain their sense of purpose (Phinney & Chesla, 2003). Efforts of family members in preserving personhood of their loved ones include "maintaining continuity" in daily routines linking their past to the present, "supporting competencies" and "protecting from incompetence" in the daily activities of living and "strategizing encounters" of people with dementia with others to validate the remaining capabilities and 'can-do' attitudes of these individuals (Perry & O'Connor, 2002). Much can be learnt from these guiding principles. With the knowledge and assistance of family members, direct caregivers at long-term care facilities can mirror similar care practice strategies to maintain and preserve the dignity of its residents- cognitively intact or otherwise (Palmer, 2013).

Palmer (2013) studied the effective ways in preserving personhood of residents in LTC with advanced Alzheimer's disease, and the influence of family caregivers in this process. In the given study, family caregivers observed several instances of direct care practices that espoused respect for the *personhood* of the residents, as well as practices that showed disrespect. Staff members supported personhood of the residents by small gestures like knowing the names of all residents, acknowledging their likes and dislikes, planning activities of interest to them, providing verbal and non-verbal compassion and care and treating them like family (Palmer, 2013). Anticipating needs of the residents and delivering appropriate individualized care was

also seen as respect for personhood, dignity and choices (Palmer, 2013). However, residents with dementia who had weak orientation, poor judgment and communication skills, were prey to care practices that disrespected and discounted their personhood (Palmer, 2013). In the same study, family caregivers noted rushed, medicalized care practices in residential facilities with little compassion towards empowering self-care and ADL completion for people with dementia (Palmer, 2013). Vulnerable residents were also deprived of basic needs such as feeding, toileting and clothing (Palmer, 2013). These inconsiderate, task-focused and quick care practices not only disregard the personhood of residents, it ultimately fosters long periods of *social death* before the actual biological death for people with dementia in LTC facilities (Palmer, 2013).

The term “social death” first appears in the 1960s with Glaser and Strauss (1966) defining it as ‘non-person’ treatment towards ‘hopelessly comatose patients’. An example of this is the nonchalant discussion of sensitive matters by hospital staff in the presence of patients, as if they do not exist; “socially he is already dead, though his body remains biologically alive” (Glaser & Strauss, 1966, p. 108). Kastenbaum (1969) defines social death as “a situation in which there is absence of those behaviors which we would expect to be directed towards a living person and the presence of behaviors we would expect when dealing with a deceased or non-existent person” (Kastenbaum, 1969, p. 15). Recent definitions of social death are more geared to the context of people with dementia, and suggest, “the harm of social death is not necessarily less extreme than that of physical death” (Patterson, 1982, p. 73). Sweeting and Gilhooly (1992) identify three groups of people that possess characteristics that qualify them to be socially dead in the society: people that suffer from lengthy, chronic illness, the very old people, and those experiencing loss of personhood. These characteristics amalgamate for people with dementia- once diagnosed, the irreversible, debilitating disease stretches till the end of life, its occurrence is likely with increased age and the diseased are repeatedly subject to dehumanized and stigmatized behavior that disregards their personhood (Sweeting & Gilhooly, 1997). Research that investigates the social lives of people with dementia notes a disparity in the interactions between people with dementia and the ones providing care for them (Kelly, 2010). The existent communicative and social abilities of people with dementia are constantly disregarded, unreciprocated or misinterpreted (Killick & Allan, 2001). People with dementia in long term care facilities are more likely to be victims of such treatment and may be perceived socially dead long before their physical death (Sweeting & Gilhooly, 1997). It is imperative for professional caregivers to model inclusionary care practices to recognize the abilities and

respect the personhood of people with dementia (Brannelly, 2011). Despite the level of chronic illnesses, cognitive capacity and physical abilities, it is the responsibility of professional caregivers to ensure social inclusion and choices through their care practices in long term care facilities.

3.2.2 The Importance of Relationships and Communication

There is a high demand for intervention of challenging behaviors such as agitation, aggression, excessive verbal behavior or wandering displayed by people with dementia (Todds & Watts, 2004). Staff assumptions and beliefs on the causes for these behaviours can influence the interventions and care offered (Todds & Watts, 2004). According to Weiner's attributional theory, a person's response to a behaviour/event is determined on their explanation of the cause of event, the emotions generated from it and the care providers' ability to control recurrence of the behaviour/event (Weiner, 1985). Care staff is more likely to provide 'helping behaviour' if cause of the challenging behaviour is influenced by external sources that could trigger similar incidents in the future (Weiner, 1985). In an event where a person with dementia is unable to verbalize their needs or desires due to loss of language and words, caregivers may interpret this behaviour as "confused and meaningless" and suppress social participation, isolating the person (Acton, Yauk, Hopkins, & Mayhew, 2007). Therefore, it is crucial to critically assess verbal (where attainable) and non-verbal communication in persons with dementia, and provide compensating care to meet their needs. It is also vital for professional caregivers to have meaningful relationships with the residents, to better understand their needs and desires and to deliver the appropriate person-centered care. Failure to recognize the needs of residents could stipulate exacerbated behaviours (Kitwood, 1997) disruptive to the care facility and stressful for the older resident.

3.2.2.1 Staff - resident interactions and relationships

The expectations on direct-care workers in long term care may be plenty: completion of large volumes of work, limited time, regimented schedules, shorthanded staff and many residents to care for (Savundrayanagam, 2014). Research has found that interactions between staff and residents with dementia are often categorized as condescending, patronizing, short, sporadic and rushed (Vasse, Vernooji-Dassen, Spijker, Rikkert, & Koopmans, 2010; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008; Williams, Herman, Gajewski, Wilson, 2009). In the spirit of task completion, front line staff is prone to ignore the psychosocial needs of the care

recipients and engage in task-focused care practices (Savundranayagam, 2014). Interestingly, people with progressive dementia have the ability to evaluate social behaviours of those around them (Sabat & Lee, 2012). This gives them the leeway to assess the attitudes and behaviours of staff and formal caregivers and differentiate between task-oriented and person-centered care practices to affect the cooperation they extend in return for this care (Sabat & Lee, 2012). Task-oriented care practices focus primarily on the job on hand, i.e. feeding the soup, administering medication, changing the clothes, while the residents' socio-psychological preferences and needs take a back seat. However, in a person-centered or "person-oriented" approach, the task is secondary and the person, personhood and psycho-social needs take precedence (Sabat & Lee, 2012). For example, tasks like bathing or toileting, while surely important, would only be subsequent to friendly communicative exchanges and interactions between the formal caregiver and resident (Sabat & Lee, 2012). Weeks & colleagues (2009) found that mental health nurses in a Scottish community after training in person-centered psychosocial counseling skills changed their care practices to 'work with their clients' instead of 'working on' them and transformed to 'listening to and hearing their clients' instead of just 'managing them' (Sabat & Lee, 2012).

In the midst of rigid, mechanical care practices, front-line staff often underestimates the practical benefits of utilizing a more person centric and communicative way to accomplish their "task" effortlessly as well as fulfill the needs and desires of the residents (Savundranayagam, 2014). Meaningful staff-resident interactions also decrease disruptive and agitated behaviours among residents with dementia, resulting in less time spent by front-line staff to comfort disturbed residents (Ashburner, Meyer, Johnson, & Smith, 2004; Carpiac-Claver, & Levy-Storms, 2007; Stein-Parbury et al., 2012).

Studies report fewer interactions between staff and residents with dementia compared to residents without dementia (Acton, Yauk, Hopkins & Mayhew, 2007; Kitwood & Bredin, 1992; Ward, Murphy, Procter & Weinman, 1992; Ward et al., 2008). These differences in interaction can be attributed to staff's perceptions about the communication abilities of people and the influence of these relations to the residents (Savundranayagam, 2014). Additionally, staff's lack of awareness, limited training on person-centered care practices (Shakespeare, 1998; Savundranayagam, 2014) and a personal bias may limit the quality of useful interactions between staff and residents. In a study to evaluate missed opportunities for person-centered communication between staff and residents, Savundranayagam (2014) found routine care practices to be one-directional where staff missed opportunities to interact, validate, negotiate or

facilitate resident needs and choices. In an effort to be more person-centered, it is essential for frontline staff to be attentive and conscious of resident behaviours, help initiate conversations, provide opportunities to be helpful and support their desires and feelings (Savundrayanagam, 2014). Actually, routine care tasks provide opportunities for staff to practice person-centered care. Encouraging residents to pick their choice of clothing or initiating dialogue about resident's life stories during less demanding care tasks are some examples of this prospect (Savundranayagam, 2014). These types of person-centered care strategies allow staff to learn about the residents during their time together, and to recognize and reaffirm the residents' perspectives, needs and abilities. Inclusion of personhood in routine tasks can not only improve the quality of care and interactions but also amend stereotypical staff perceptions about aging, people living with dementia and their approach to care (Killick & Alen, 2001; Kitwood, 1997; Sabat, 2001)

Empirical evidence on relationship-centred care supports the significance of staff relations on the quality of life of LTC residents (Bowers et al., 2007; Doty et al., 2007). In a narrative research, Gubrium (1993) found that residents place greater value on relationships in their lives versus the quality of care they receive in nursing homes. This, in combination with social interactions and "feelings of purpose" to their existence interpret their dynamics in care facilities (Gubrium, 1993). Nonverbal interactions (smiling, touching, etc.), nurturing behaviour and reciprocal actions by staff members has been found to reduce agitation and kindle calmness amongst residents (Brown, 1995; Burgener & Barton, 1991; Burgener, Jirovec, Murrell & Barton, 1992; Hallberg, Holst, Normark & Edberg, 1995). Brown (1995) highlighted three effective non-verbal caregiving strategies that mollified residents' agitation; 1) being with the resident in time of aggression, 2) adapting care techniques in response to the resident's given situation, and 3) extending care beyond the "task". While these examples of care practices are not oblivious to person-centered care, its recognition as relational care gives prominence to expanding the focus of interpersonal relationships in long-term care facilities

3.2.2.2 Verbal and non-Verbal Communication

Key policy initiatives in the United Kingdom identify quality of life and communication to be main areas of concern in dementia care (Department of Health, 2009). People with dementia demonstrate concerning behaviours that are often responded by poor communication from caregivers, which in turn cause more disruptive behavior amongst them (Young, Manthorp, Howells & Tullo, 2011). This "downward communicative spiral" is driven by a focus on lost

abilities with little attention to the remaining capabilities of these individuals (Lubinski, 1995). Empirical evidence confirms that effective communication can improve the quality of life of people with dementia and those living in long term care facilities (Young et al., 2011).

Recurrently, older adults are at risk of being recipients of ageist communication as a consequence of orthodox expectations of 'incompetence and dependence' (Savundrayanagam, Ryan, Anas & Orange, 2007). The Communication Predicament of Aging Model (CPA) proposes that communication styles, speech and language are often determined by age stereotypes based on the individuals' physical appearance, chronological age, presumed abilities and deficits and social settings (Coupland, Coupland, Giles & Henwood, 1988; Ryan, Meredith, MacLean & Orange, 1995). Small (2006) suggests that both positive and negative stereotypes and perceptions of aging can influence communication behaviours of younger adults when addressing older adults, however research indicates the latter to be more prevalent (Small, 2006).

Caregivers and staff of older adults often resort to over-accommodated communication based on their perception and imprudent views of aging when interacting with residents in long term care facilities. Some prominent features of this typecast communication include the use of 'simple vocabulary, simple grammar, exaggerated intonation, diminutive naming, high pitch, restricted topics, exaggerated praise, non-listening and avoidance' (Hummert & Ryan, 2001; Williams & Nussbaum, 2001). These researchers suggest that "elderspeak" (i.e. infantilization or secondary baby talk) - synonymous to over-accommodated communication- is a common style of communication between staff and residents in long term care facilities (Williams, Kemper & Hummert, 2003; Williams, Herman, Gajewski & Wilson, 2009). Elderspeak includes using simple vocabulary or grammar, short sentences, elevated pitch and volume, slow-paced speech and using unnecessary terms of endearment such as "honey" or "good girl" (Kemper & Harden, 1999). Research on elderspeak indicates that frequent occurrences of such communication negatively affects the older adults' social participation and involvement in activities, as well as destructs their self-esteem and sense of control (Kemper & Harden, 1999). Unfortunately, residents living in long term care with cognitive impairments are at further risk of this communication quandary (Savundrayanam et al., 2007). It is known that residents with cognitive inabilities show promising skills when their personal history, skillsets and non-infantilizing communication tactics are utilized to capture their strengths (Savundranayagam et al., 2007). Person-centered communication is perceptive to these features and focuses on the

personhood, health and well-being of individuals instead of the decline in physical and cognitive abilities (Savundrayanagam et al., 2007).

Kitwood (1997) proposes communication behaviours to include recognition, negotiation, collaboration, facilitation and validation to honor the personhood and dignity of older adults. Savundrayanagam and colleagues (2007) provide best-practice examples of these behaviours: recognition means care staff acknowledges each resident's uniqueness, distinguishes them by their names and offers direct eye contact, personalized greeting/listening etc. Negotiation tactics proposed by staff allow residents with dementia to have control over their choices, preferences, desire and needs in daily living. Collaboration encourages staff-resident interactions by working together in task completion, and maximizing retained abilities of people with dementia. Facilitation involves staff to identify and ease the process of attempted actions of people with dementia, and ensure their desires and needs are initiated and fulfilled. Lastly, validation recognizes and confirms the feelings of persons with dementia and shows empathy and consideration towards them (Savundrayanagam et al., 2007). Utilizing these guidelines enables staff to provide person-centered communication as well as create dialogue and trust with residents. These communication practices protect the resident's personhood and also optimize comprehension and understanding in people with dementia.

Health care professionals propose many common communication strategies useful to persons with dementia (Small, Gutman, Makela & Hillhouse, 2003). Conversations that comprise of short sentences, yes-no questions and simple syntax can encourage rich discussion and knowledge exchange amongst staff and residents (Ripich & Wykle, 1996; Santo Pietro & Ostuni, 1997). People with dementia may be able to listen and comprehend more effectively with 1) simple sentences without clauses, 2) semantic substitutions and simplified linguistics, 3) repetition and summary of grammatically complex sentences, and 4) open-ended and close-ended questions geared toward semantic and not episodic memory (Ripich, 1994; Small et al., 2003; Small & Perry, 2005). Rochon and colleagues (1994) found using one idea per sentence also enhanced the level of understanding for people with dementia. Increase in person-centered communication and decrease in task-focused communication improves resident satisfaction and quality of life and lessens disruptive and "challenging" behaviours in long term care residents (Acton et al., 2007). While some of these approaches may be over-accommodative due to its childlike nature (Savundrayanagam et al., 2007), employing person-centered communication techniques and maintaining dignity for people with dementia is

dependent on the education and training levels of staff and caregivers (Savundrayanagam et al., 2007) and their will to put the person before the task.

In addition to verbal communication strategies, advocates of person-centered care highlight the value of non-verbal communication and body expressions to provide empathic and considerate dementia care. Recommended nonverbal communication strategies include establishing eye contact, using gestures for effective guidance, sitting face to face, making overstated facial expressions, using a calm tone, limiting environmental distractions, utilizing touch tactics with individuals to execute tasks, moving slowly, and giving a person adequate time to respond (Bartol, 1979; Beck, Heacock, Rapp, & Percer, 1993; Goldfarb & Pietro, 2004; Sheldon, 1994; Small et al., 2003)

Kontos and colleagues (2007) stress the importance of the communicative ability of the body, suggesting a care reform that includes the imagination of the caregiver to connect to the “personhood” of persons with dementia and provide sympathetic care. This occurs through shared bodily experiences between carers and receivers, to acknowledge gestures, actions and habits that express individuality and selfhood (Kontos & Naglie, 2007). A qualitative study to understand staff interaction with non-verbal cues and bodily imagination, found carers to use personal experiences to diagnose and address the needs of older adults; using the *power of a hug* to put the resident at ease (Kontos & Naglie, 2007). These shared experiences form a connection between the caregivers and recipients to promote a person-centered approach to care (Kontos & Naglie, 2007). Body expressions and gestures signal care providers with the mood and thought of the residents. Kontos (2012) found gestures such as a gaze, to look in a certain direction and movement of arms and legs to be key indicators of conversation start-ups amongst residents. Certain gestures also marked displeasure or unhappiness in a conversation; while gazing directly was a prompt to start conversation, looking away was a sign that the conversation had ended (Kontos, 2012). Recognition of non-verbal cues and bodily experiences help care staff identify cues of unmet needs, and proactively imply person-centered to prevent disruptive infuriation.

Visual cues may also be a vital trigger of communication opportunity between staff and residents. Williams and colleagues (2011) learnt that display of historic, personal photographs in resident rooms were great to initiate meaningful interactions between resident and staff. The study revealed that the pictures prompted conversations on interpersonal topics, staff-resident

engagement and opportunities of reminiscence for individuals. This example adds to the realms of options possible for person-centered dialogue and relationships in care home settings.

3.2.3 Non-Pharmacological care

Supporting individuals to maintain their identity in long term care facilities has been linked with positive self-esteem and quality of life for the residents (Davies, 2001; McKee, Downs, Gilhooly, Gilhooly, Tester & Wilson, 2005). Specific psychosocial and creative therapies such as reminiscence, music therapy, life story work and oral history can be useful to promote 'meaningful occupation' for the person in LTC (Fossey, 2008). These biological and social approaches can provide opportunities for residents to reaffirm identity, improve communication skills, increase self-expression, and have meaningful experiences to enhance and preserve their personhood (Fossey, 2008). Research suggests that purposeful and organized social, physical and creative activities can positively impact the social interactions of people with Alzheimer's Disease in care homes (Marshall & Hutchinson, 2011).

Backhouse and colleagues (2014) found reminiscence to be the most practiced non-pharmacological intervention amongst persons with dementia, followed by music therapy and animal/pet therapy. Other interventions of care such as one-on-one activity, outings and occupational therapy were also applied (Backhouse, Killeth, Pehnale, Burns & Gray, 2014). The triumphs of the Eden Alternative facilities also confirm therapeutic interventions to increase social engagement and reduce boredom and loneliness (Sampsell, 2003). However, non-pharmacological interventions require more time, training, costs and skillsets within LTC, which limits its immediate execution despite promising evidence for improved quality of life for residents, especially for people with dementia (Backhouse et al., 2014; Moniz-Cook et al., 2012; Whitaker et al., 2013). In order to gain more insight, the subsequent sections will discuss three therapeutic interventions- reminiscence, creative therapy i.e. music therapy and multisensory therapy as effective therapeutic and non-pharmacological person-centered care practices with residents in LTC.

3.2.3.1 Reminiscence

Long-term care staff utilizes many pharmacological and non-pharmacological techniques to alleviate behavioural and emotional disturbances amongst residents. Reminiscence therapy, a type of psychotherapy, is a practice to recall past memories and life events to encourage positive feelings and good thoughts amongst participants, directed to an improved quality of life

and better adjustment to present-day situation (Bulechek, Butcher, & Dochterman, 2008; Westerhof, Bohlmeijer & Webster, 2010). Reminiscence is therapeutic when communication occurs between two or more individuals to achieve person-centered goals (Elias, Cert, Neville, & Scott, 2015). Features of reminiscence therapy is flexible; it can be structured or unstructured, in a group or individual setting, can focus on happy or sad memories and can be implemented in various settings and during daily life activities i.e. at mealtimes or exercise (Gibson, 2011; Klever, 2013; Stinson & Kirk, 2006). Typically, during reminiscence therapy, participants are at liberty to freely discuss their life memories in hopes of gaining personal insight and a sense of identity accumulated during their life course (Gudex, Horsted, Jensen, Kjer, & Sorensen, 2010; Klever, 2013). Literature research identifies three types of reminiscence therapies- simple reminiscence, life review and life review therapy (Webster et al., 2010; Westerhof et al., 2010). Simple reminiscence is usually unstructured with the aims to increase social-wellbeing of the participants (Webster et al., 2010; Westerhof et al., 2010). Alternatively, life review is more structured and concentrates on the positive and negative life events and memories of the participants (Elias et al., 2015). Life review therapy is more advanced and used to treat a particular problem for the participants (Burnside & Haight, 1994).

Reminiscence is known to have a positive impact on people with dementia and improve their quality of life (Gibson, 2011; Schweitzer & Bruce, 2008) through interactive conversations, social engagement, and participation in meaningful activities (Cotelli, Manenti & Zanetti, 2012; Lai, Chi & Kayser-Jones, 2004). Reminiscence therapy also works well for people in later stages of dementia as it taps on their intact early memories of life and promotes interaction and communication in the present time (Gibson, 2005; Woods, Spector, Jones, Orrell & Davis, 2005). Reminiscence can be performed through conversational skills as well as non-verbal skills such as generic photographs for storytelling, videotaped biographies, family objects, music, or sensory items to prompt recall in persons with different stages of dementia (Davis & Shenk, 2015; Wood, 2005). Empirical evidence confirms the positive outcome of reminiscence therapy on people with dementia. A Cochrane review of reminiscence therapy indicated an improvement in cognition, mood and behaviours such as self-care and communication as a result of reminiscence for people with dementia (Woods et al., 2005). Another systematic review specifically aimed to study the impact of psychosocial interventions on the behavioral and psychological behavioural symptoms (BPSD) of people with dementia, reiterated reminiscence therapy to positively influence moods of the recipients (Testad, et al., 2014). Subramaniam & Woods (2012) found similar results in systematic review- evidence supported a positive impact

of reminiscence on mood, cognitive abilities and overall well-being for people with dementia, especially if life review or person-specific reminiscence was applied.

Cooner and colleagues (2014) conducted a grounded theory study to assess the potential benefits of reminiscence on staff-resident interactions in LTC living with dementia. Results implied reminiscence to be effective as it permitted staff to “see” and “know” the person beyond the scope of the irreversible disease. In the same study, reminiscence therapy capitalized the spectrum of communication and engagement between staff and dwellers (Coonor et al., 2014). The therapeutic benefits of this practice helped staff to understand and appreciate the ‘person’ as well as familiarize with the residents’ preferences and choices, their life achievements, and unique characteristics (Coonor et al., 2014). The results of the study voiced the importance of communication between care staff and residents. Coonor and colleagues (2014) argued that through reminiscence, staff found a structure and purpose for communication with the care recipients. The study also confirmed previous evidence that reminiscence therapy provided opportunity for staff and formal caregivers to value the person beyond dementia (Shweitzer, 2003; Gibson, 2011; Coonor et al., 2014). Moreover, residents also benefitted from the reminiscence activities through increased social participation and pleasurable activities and decreased challenging behaviours (Coonor et al., 2014).

Reminiscence therapy also resonates with families of residents with dementia in care homes. Often times, as explained by Bowers (1988), relatives of people with dementia burden themselves to preserve the personhood of their loved ones in residential care facilities, to maintain their dignity and choices i.e. offer ‘preservative care’. Reminiscence supports this type of care as staff is better informed of residents’ past, achievements, joys and sorrows and is better equipped to provide person-centered care. Reminiscence therapy also provides a platform for family involvement and promotes their invaluable contribution to the residents’ life story (Cooney et al., 2014).

Reminiscence therapy, although flexible in nature, is time consuming and may be burdensome for staff with busy schedules and task-focused care regiments (Cooney et al., 2014). Given the promising outcomes of this non-pharmacological care on residents within a facility- increase in social engagement and positive outlook on life along with a decrease in challenged behaviors- sustaining reminiscence therapy hugely relies on organizational culture and the facilities’ care values (Cooner et al, 2014). Empirical literature indicates unstandardized protocols of reminiscence therapy limit its implementation in LTC settings (Stinson & Long,

2014). Care staff also note inadequate training in how to organize, facilitate and assess reminiscence therapy as barriers to its implementation (Stinson & Long, 2014). Therefore, in order to implement, maintain and sustain this type of person-centered care approach, it is essential for organizations and management to prioritize reminiscence therapy into their practice of care and provide care staff with the appropriate skillsets to execute this mode of intervention.

3.2.3.2 Creative Expressions - Music therapy

Non-pharmacological interventions aim to meet the needful requirements of residents in long term facilities. Creative expression programs such as arts, music, storytelling, drama and dance and movement combat boredom and confusion for the dwellers, especially those with dementia (Burgio et al., 1994; Ice, 2002; Phillips & Conn, 2009). By definition, creative expression programs facilitate resident participation in “something new”- these may include arts and crafts performances based on an original idea or perspective (Phillips & Conn, 2009). Creative expressions stipulate communication, social integration, self-expression, sensory stimulation and emotional consolation amongst participants in a friendly, non-judgmental and stress free environment (Phillips & Conn, 2009). For people with dementia, creative therapies provide alternative means of expression in the absence of liberated ability to vocalize their thoughts and emotions (Phillips & Conn, 2009).

Amongst the diverse creative expressions, music therapy is known to be the most popular with a higher rate of implementation and the strongest research base (Phillips & Conn, 2009). As defined by The Canadian Association for Music therapy, it is

“...the skillful use of music and musical elements by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health. Music has non-verbal, creative, structural, and emotional qualities. These are used in the therapeutic relationship to facilitate contact, interaction, self-awareness, learning, self-expression, communication and personal development” (Canadian Association for Music Therapy, 1994).

Personalized music interventions may also stimulate the intact *remote memory* of individuals with dementia and provoke positive feelings and calming effects that were once associated with that type of music (Gerdner, 2005). Furthermore, interaction with familiar and preferred meaningful music in a long term care setting was found to smoothen resident’s transition into their new home and provide a source of comfort to face the issues that arise from dementia and/or other physical, psychological and emotional conditions (Kydd, 2001). Anecdotal evidence suggests that music stimulates reminiscence, encourages dialogue and

communication, promotes positive feelings and reduces agitation and anxiety for the participants (Phillips & Conn, 2009).

Several research studies show promising benefits of music therapy for residents of long term care. Music interventions such as singing, dancing and playing instruments have been found to lead to significant decrease in agitation amongst participants (Brotons, Pickett-Cooper, 1996; Svansdottir & Snaedal, 2006). Research also confirms music to decrease aggressive and disruptive behaviors of residents in diverse settings and specific activities such as during meal times and bath times (Gerdner, 2000; Hicks-Moore, 2005; Sherratt, Thornton & Hatton, 2004). Individualized music therapy resulted in increased social interaction during and after the therapeutic sessions for eight residents with Alzheimers Disease (Pollack & Namazi, 1992). Myskja & Nord (2008) found a significant decrease in depression scores amongst residents when music therapy was resumed after a few months in a long-term care facility. Similarly, Takahashi & Matsuhita (2006) found lower systolic blood pressure and better physical and mental state in residents who received music therapy once a week for two years, compared to those who received none. Clair & Bernstein (1990) found exposure to music therapy once a week for 15 months was effective for three males with Alzheimer's disease, despite their cognitive and social decline with the progression of the disease. In a randomized case-control study, Svandottir & Snaedal (2006) reported a decrease in aggressive behaviours and anxiety amongst residents with moderate to severe Alzheimer's disease who participated in music therapy three times a week for six weeks. Similarly, another study reported significant decrease in agitated behaviours amongst residents with moderate to severe dementia was noted, following participation in music therapy for thirty minutes, biweekly for four weeks (Sung, Chang, Lee & Lee, 2006).

Despite substantial evidence to support the positive effects of music therapy for people living with dementia, the long term effects of its efficacy is understudied (Cooke, Moyle, Shum, Harrison, & Murfield (2010). Ledger & Baker (2007) reported no significant differences in agitated behaviors over a period of one year for the group who received regular music sessions compared to those who received usual care. Similarly, Berger et al. (2004) found zero effect of music on the mental and behavioral functions of people with dementia exposed to music for over two years.

Overall, music therapy has showcased short-term, multiple benefits for older adults in LTC. Research confirms it decreases agitation and use of psychotropic medication (Ridder,

Stige, Qvale, & Gold, 2013), reduces symptoms of depression (Ray & Mittleman, 2015), increases personal engagement through music enhanced communication (Raglio et al., 2008), reduces negative behaviors and enhances positive social interactions (Ziv, Granot, Hai, Dassa, & Haimoc, 2007), improves social behaviors like eye contact and smiling (Lesta & Petocz, 2006), and positive effects the wellbeing and quality of life of residents with dementia (Sarkamo et al., 2013; Ziv et al., 2007). In addition to being therapeutic, empirical evidence credits music as a valuable means of communication that remains intact for people with progressive cognitive decline (Sambandham & Schirm, 1995). To reap the multiple advantages of music therapy, Kydd (2001) recommends making it available to everyone in the care home facilities. Music therapy would be most successful if it caters to the participant's musical preferences, taps on intact skills (i.e. singing, playing instruments, recalling lyrics, making choices) and makes them feel successful and welcome in their journey of music (Kydd, 2001).

3.2.3.3 Multisensory Stimulation Environments (MSSE) - SNOEZELLEN®

The use of controlled multisensory stimulation environments, also known as snoezelen has become very popular in recent times. Hulsegge and Verheul (2005) initially established this approach of non-pharmacological care in the Netherlands in the 1970s, to reduce stressful behaviours in severely disabled persons with learning difficulties (Burns, Cox & Plant, 2000; Cavet, 1994; Hogg, Cavet, Lamber & Smeddle, 2001). Since then it has been an effective intervention and platform for social interaction, leisure and recreation activities for older adults with dementia (Ball & Haight, 2005). The word snoezelen is a combination of two Dutch words that mean "sniffing and zoding" (Hulsegge & Verheul, 2005). Ideally, a snoezelen room is specifically designed as a multisensory stimulation environment (MSSE), with dim lights and soft music to appeal to the individual's primary senses (Hulsegge & Verheul, 2005). This type of therapeutic space typically includes objects that ignite multisensory stimulation through various objects like fiber-optic cables, aromatherapy, different music and sounds, textured balls, soothing and adjustable lighting, screen projectors, water columns of different colors, mirrors, various tactile objects, antigravity rocking chair and mirror balls (Milev, Kellar, & McLean, 2008; Ward-Smith, Llanque & Curran, 2009). It aims to provide its users a pleasurable stress-free sensory experience without any cognitive activity or verbal communication solely for the purposes of relaxation and stimulation (Burns et al, 2000; Chitsey, Haight, & Jones, 2002).

According to Chung & Lai (2002), "Snoezelen is commonly employed as a therapeutic modality in dementia care in four areas: (1) reducing maladaptive behaviours and increasing

positive behaviours, (2) promoting positive mood and affect, (3) facilitating interaction and communication, (4) promoting a caregiving relationship and reducing caregiving stress.” The MSSE provides people with dementia the opportunity to explore their tactile environment at their own pace, in their own time, without the demands and pressures of unrealistic expectations (Pinkney, 1999).

Often times residents with dementia in LTC face overstimulation or sensory deprivation, which in turn impacts their behaviour and negative attitudes (Sanchez, Jose, Millian-Calenti, Lorenzo-Lopez & Maseda, 2012). Kovach (2000) elucidates that the disparity in the sensory-stimulating and sensory-calming activities offered to individuals with dementia commonly results in intrapsychic discomfort leading to agitation and premature decline in their social and physical activity. To combat this discrepancy, a more optimum “sensoristasis” i.e. a balanced sensory stimulating environment is useful (Kovach, 2000). Snoezelen or MSSE are interventions that provide a relaxing and nondirective environment for people with dementia and encourage older adults to pace and “engage with sensory stimuli of their choice” (Baker et al., 2001; Chitsey et al., 2002). The elements of MSSE resonate with the ethos of person-centered care in that it acknowledges the personhood of the participants, stipulates choice and preference in engagement, is client-centered, promotes decision-making and places greater importance on the relationships than the task of doing (Baker et al., 2001; Edvardsson, Windblad & Sandman, 2008). MSSE appeals to the primary senses in a trusted and tranquil environment without the need of any intellectual or verbal contribution (Burns et al., 2000). Participation is dependent on nonsequential, momentary interaction with stimuli with no burden of remembering the chain of events (Baker et al., 2001). These features of MSSE promise more viability for people with severe dementia whose communication abilities may be restricted in the later stages of the disease (Finnema, Froes, Ribble, & Van Tilburg, 2000).

Limited empirical evidence examines the benefits of MSSE for people with dementia in long-term care with inconclusive findings. Riley-Doucet (2009) conducted a qualitative study with ten individuals with dementia and their family members to examine the effectiveness of MSSE. Results showed satisfaction amongst participants; people with dementia were calmer, more relaxed and receptive to their surroundings and family members, and showed positive behaviours. Milev and colleagues (2008) found that people with dementia exposed to MSSE interventions 1-3 times a week scored better on behavioural outcomes, compared to the control group. The results indicated that including MSSE to the care practices could be a beneficial tool for LTC dwellers.

Similarly, van Weert and colleagues (2005) found significant improvement in behaviours of recipients of MSSE after a 15-month intervention. They recorded lower levels of aggression, rebelliousness and apathetic behaviours compared to the control group. Cruz et al. (2011) investigated the impact of motor and multisensory stimulation on LTC residents and found an increase in resident engagement in the morning routines, but not significant results. Other empirical research also illustrates short-term improvement in moods of people with dementia exposed to MSSE, however the long-term benefits are not clear (Baillon, Van Diepen, Prettyman, Redman, Rooke & Campbell, 2004; Cornell, 2004; Cox, Burns & Savage, 2004; Hope, 1998).

While snoezelen or MSSE aims to improve the users' verbal and non-verbal communication, empirical evidence to support this claim is inconclusive. While Hope (1998) did find MSSE interventions to be prospects for increased and meaningful interaction as well as greater communication spontaneity and greater eye contact, Baker and colleagues (2001) did not gather sufficient evidence to conclude a significant difference in communication between the participants and the control group. However, van Weert et al. (2005) found considerable improvements in verbal and non-verbal communication between recipients of MSSE interventions and their caregivers, and suggested its beneficial inclusion in the practice of daily care. Residents who received MSSE displayed more affection, greater eye contact, improved decision-making, quality interactions with caregivers and full-sentence communication compared to the control group. They also displayed less agitation, anger and verbal disapproval (van Weert et al., 2005). Similarly, Cruz and associates (2011) found an increase in resident engagement through caregiver-direct gaze, reduction of close eyes and increased laughter, but failed to draw statistically significant results before and after the intervention.

Despite limited empirical evidence to support the long-term effects of multisensory therapeutic interventions for residents with dementia at LTC, its emergence as a beneficial source of non-pharmacological care is strong. Studies have successfully cited the short-term implications of this practice and its potential for success in the future once the intervention process is systematically established (Sanchez et al., 2012).

3.3 Organizational Issues

In the last decade, the long-term care industry has acknowledged the necessity for reevaluation and transformation of nursing homes to embrace older adult autonomy and independence thus giving rise to a culture change movement (Koren, 2010). Organizations that adopt culture change base their values and beliefs on “personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment” (Crandall, White, Schuldheis, & Talerico, 2007, p. 47). While person-centered caregiving is a process, the objective is to improve the well-being and quality of life of the residents (Tellis-Nayak, 2007).

Leaders and researchers in long-term care discuss various workplace-related issues in such organizations (Tellis-Nayak, 2007). Traditionally, LTC organizations use a biomedical model of care and primarily focus on physical care tasks and medication management instead of initiating organizational change (Canadian Healthcare Association, 2009). Inadvertently, LTC organizations exhaust their energy to comply with systematic and regulatory guidelines, focusing on detailed aspects of care to resolve urgent individual needs, instead of addressing problems at an organizational level (Institute of Medicine, 2001; Ontario Ministry of Health and Long Term Care, 2009). LTC staff often report ineffective communication, inconsistent monitoring of processes of care, and untimely responses to resident needs as organizational issues that stipulate errors, poor clinical outcomes and resident dissatisfaction (Rhode Island Quality Partners, 2002; Coleman, 2003; Grant, 2008; Canadian Healthcare Association, 2009). Staff burnout, a common byproduct of the excessive workload and job stress in residential care, also intensifies emotional exhaustion, depersonalization, feelings of poor personal accomplishment and high staff turnover (Evers, Tomic, & Brouwers, 2002). Time-sensitive, labor-intensive tasks trigger job strain amongst direct care providers such as nurses and care aides, and cause job dissatisfaction and dwindling workplace commitment (Ingersoll, Olsan, Drew-Cates, DeVinney, & Davies, 2002; Morgan, Semchuk, Stewart, & D’Arcy, 2002).

Shaller (2007) developed a framework proposing seven key factors to overcome work-related issues and achieve patient-centered care in health care at the organizational level. These include engagement of top leadership; a strategic vision shared with every person in the organization; staff and family engagement at multiple levels; a supportive work environment for

all care providers; systematic measurement and feedback mechanism; a conducive built environment; and supportive information technology (Shaller, 2007). While these indicators are focused on healthcare and patients in acute settings, this framework is pertinent to long-term care facilities, and serves as a guiding tool to emphasize the person-centric organizational strategies valuable in resident satisfaction and well-being.

Adopting a more person-centered caregiving approach encourages long-term care organizations to move away from the archaic institutional bureaucracy, authoritative decision-making, dissatisfied employees, institutional interiors, and constrictive environmental design. To achieve culture change and organizational transformation, Tellis-Nayak (2007) emphasizes the role of administrators and directors of long term care to facilitate staff engagement and motivate direct care workers to evolve in the workplace and deliver quality care. Furthermore, some research studies also reflect on the structural factors in long term care that improve or support the social system for staff and caregivers; adequate and consistent staffing and self-managed teams enhance quality of care, empower staff and increase job satisfaction and commitment. (Barry, Brannon, & Mor, 2005; Castle, 2001; Castle & Engberg, 2005; Riggs & Rantz, 2001; Yeatts, Cready, Ray, DeWitt, & Queen, 2004)

This section will review the organizational facilitators and barriers in implementing person-centered in long term care settings. The *culture change movement*, *staff training and communication skills*, and *the environmental design* facilitate homelikeness and individualized care in long-term care facilities. Despite its widespread popularity and benefits, person-centered care faces several organizational barriers for implementation. The *structural*, *environmental*, *systemic* and *personal limitations* will also be evaluated. Finally, this section will also review the benefits of person-centered care to the multiple stakeholders, i.e. the care providers and care receivers.

3.3.1 Organizational Facilitators for implementing Person-centered Care

3.3.1.1 The “Culture Change” Movement in Long- Term Care

Long-term care models in the 1960s, following the Hill-Burton Act of 1946, mirrored hospital style hierarchical and autocratic management styles (Brune, 2011). Hospitals, nursing homes, and retirement communities were all designed to be cost-effective, institutional, and regulation-compliant with a focus on healing, palliative care, physical ailments or mental impairments of the “patients” (Brune, 2011). The residents were, and to some extent still are,

isolated from friends and family, community involvement or social interaction. (Brune, 2011). Invariably, most nursing homes or long-term care facilities prior to the 1990s patterned the hospital-like atmosphere with sterile environments, structured routines, and limited opportunities for staff-resident interactions or personal growth (Brune, 2011).

However, in 1986 the Institute of Medicine Report, "Improving the Quality of Nursing Home Care" emphasized the importance of 'home' as opposed to the 'nursing' element in nursing home services (Vladeck, 2003). Following this, in 1987, the federal Omnibus Budget and Reconciliation Act (OBRA) in the United States contained the Nursing Home Reform Act, which revamped the federal requirements for LTC facilities and introduced a 'minimum standard of care' for those living in certified care facilities (Brune, 2011; Calkins, 2002). The Act was developed with the intent of promoting resident satisfaction through standardized assessments, detailed care plans, reduction of restraint and quality indicator reports. As a result, the statutory requirements enforced organizations to provide services and care that optimized resident well-being, in essence introducing a phenomenon now called "person-centered care" (Kelly, 1989). However, an accidental consequence of this increased emphasis on quality of care in nursing homes focused on medical outcomes as opposed to the residents' psychosocial aspects of quality of life (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). Hence, the medical model of care strengthened and endured in long-term care facilities.

With the emergence of the baby boomers, various care providers, advocates, researchers and regulators challenged the notion of long term care facilities as medicalized institutions. A paradigm shift in long term care occurred in the 1990s called the culture-change movement (Brune, 2011). Culture Change refers to the national movement of the transformation of older adult services to a person-centered care approach (Brune, 2011). The fundamental goal of culture change in LTC is to modify policies, practices, values and beliefs to provide residents with more respect, autonomy and choices throughout the day, as well as empower front line staff to provide optimum care (Jones, 2011). The implementation of culture change is unique to each provider; the key concept is to identify the uniqueness and personhood of residents in LTC, as well as value the time, personhood and contributions of the care staff directly providing the care (Maslow et al., 2013). The culture change journey is not one with a final destination, but instead a method of ongoing quality improvements to better the lives of the residents (Nikki, Kolanoswki, Milone-Nuzzo & Yevchak, 2010). It is believed that the shift from a traditional model of care through culture change fosters desirable health and quality of life outcomes amongst residents in long term care facilities (Nikki et al., 2010).

Since inception, several care models have adopted a culture change philosophy and been founders of the change: the Pioneer Network, the Eden Alternative, the Wellspring Innovative Solutions, the Beverly Culture Change Pilot, the Greenhouse project, and the HATCH model, to name a few (White-Chu et al., 2009). The *Eden Model* thrives on inclusion of the human habitat with continuous contact with people, plants, animals and children as well as architectural changes (Coleman et al., 2002). *The Greenhouse* focuses on architectural changes that promote person-centered care in small homes, with self-directed teams responsible for care and meal preparation, resident-directed choices and care as well as close contact with staff and residents (Zimmerman & Cohen, 2010). *Wellspring* uses learning collaborative techniques across alliance of independent LTC facilities to share management expertise, tactics to train and empower staff, and a reporting system to track performance data (Stone et al., 2002). Based on the commonalities of different initiatives and the core concepts of culture change, three key elements are identified as crucial to culture change -- workforce redesign, resident-centered, individualized care and resident choice (White-Chu et al., 2009). White-Chu and colleagues (2009) discuss the culture change revolution in depth, stressing the importance of resident and direct care staff relationships, “buy in” across all disciplines on the value of person-centered care, and the leadership’s commitment to undertake this lengthy and sometimes challenging journey of culture change.

A mixed methods study to identify reasons for adapting culture change found demographic changes, institutions’ mission, state regulations, financial gains, and improving quality of life for its residents as motivating factors for implementation (Shield, Looze, Tyler, Lepore, & Miller, 2014). Crandall and colleagues (2007) found that culture change required transformation in the core mission of the organization, redesigning policies, procedures, job descriptions and care plans, delegating project leadership and non-hierarchical decision making and the openness to doing things differently. For example, in an organization’s attempt to implement person-centered care, the entire meal delivery system was redefined by extending breakfast hours, preparing customized meals based on a menu selection and introducing snack carts throughout the day (Crandall et al., 2007). Another facility embraced culture change by enforcing ambitious physical changes such as installing a wireless network for care staff, adding furniture, wall décor and fixtures to give a homelike appearance to the facility, and creating private spaces for family interaction, social engagement and contemplation (Shield et al., 2014).

Leadership is a critical theme in culture change. Leaders, directors, administrators of long term care facilitate culture change by translating abstract ideas to tangible practices and

policies, provide encouragement and direction to all levels, and maintain momentum and excitement for implementation (White-Chu et al., 2009). The culture change movement thrives on leaders to empower staff and residents, and progress from a hierarchical management style to a flattened leadership approach. Research demonstrates that long term care facilities with more credentialed administrators and leaders have better quality of care than those facilities with less qualified leaders (Trinkoff, Lerner, Storr, Joahntgen, Gartrell, 2015). The leadership team is instrumental in reducing staff turnover by recognizing and motivating direct care workers, providing opportunities for retrospection and feedback, and making staff and frontline workers feel valued and appreciated (Eaton, 2001; White-Chu et al., 2009). Evidence suggests that effective managerial practices, consumer commitment, and flexibility take precedence over wages in motivating staff to do well in the workplace (Howes, 2008; Tellis-Nayak, 2008). During the culture change process, the supervisors and leadership play a dual role as implementers of the change as well as recipients of the innovative process. In order for successful implementation of culture change in facilities, it is essential to examine the competencies of current managers/supervisors and alter the recruitment and selection process accordingly (Berkhout, Boumans, Mur, & Nijhuis, 2009).

Several studies assessed the outcomes of culture change on resident well-being. Research indicates that implementation of the Eden Alternative has many benefits for the residents, staff and families. Residents are more active and perceptive to activities, interactions and communication, with reduced need for antidepressant medication (Roshier & Robinson, 2005; Sampsell, 2003). Front-line staff has more power in decision-making and organization, resulting in decreased staff absenteeism and increased job satisfaction (Sampsell, 2003). Family members of residents are more appreciative of the non-sterile and atypical care environment resulting in increased visitation, participation and satisfaction (Drew & Brooke, 1997; Roshier & Robinson, 2005; Sampsell, 2003). However, a study to investigate the levels of boredom, helplessness and loneliness in an Eden facility found lower levels of self-reported boredom amongst cognitively intact residents but no differences in loneliness after a one-year implementation (Bergman-Evans, 2004).

Nikki and colleagues (2010) found a mix response to psychosocial health outcomes- while some studies showed a decline, a few demonstrated improvements in psychosocial health among residents through the positive influence of a culture change model. A study examining the greenhouse approach confirmed enhancement in quality of life indicators, better emotional well-being and decreased incidence to late-loss ADL decline after a two-year implementation

period (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Grant (2008) reported higher levels of autonomy and resident choices amongst residents living in resident-centered facilities compared to those living in non-resident centered facilities.

Culture change in long term care may be more widespread if incremental changes were initially introduced as opposed to practices that are more difficult to execute (Sterns, Miller & Allen, 2009). Success of early initiatives may lead to “buy in” from staff and residents and build a platform for more complex and sensitive culture change practices. A study of Illinois long-term care facilities documented that a higher proportion of facilities comfortably introduced small culture change practices statewide. Their research indicates that when adopting culture change, more facilities offered residents choices at mealtimes or options of when to wake up or sleep compared to the fewer facilities that welcomed big changes like staff engagement in key management decisions (Severance, 2006).

Culture change thrives on the unique relationship between direct care staff and the residents to facilitate person-centered care (Jones, 2011). LTCs may choose a personalized approach to culture change that fits their needs, strategic plan and budget. When organizations are able to transform “hard-wired” medical model beliefs of leadership and care staff to a more individualized and sensitive type of care, a true culture change can be accomplished.

3.3.1.2 Staff training and communication skills

Staff stability and continuity of care are critical in sustaining person-centered care and other quality efforts (Center for Excellence in Assisted Living (CEAL), 2010). Caregivers of persons with dementia are at risk of higher levels of stress, burnout, and emotional exhaustion, adversely affecting the care recipients and quality of care provided (Duffy, Oyebode, & Allen, 2009; Todd & Watts, 2005). In a study to evaluate the effects of training on elderly care paraprofessionals, it was found that lack of training was an “unmet need” and that improving this aspect could help reduce strain and burnout for these professionals and increase quality of care (Stevens-Roseman & Leung, 2004).

There have been many intervention efforts to provide communication skills training for formal caregivers of people with dementia. Since residents in long term care often lose their ability to communicate effectively and exhibit disruptive behaviors due to unmet needs (Algase et al., 1996), it is important for caregivers to be trained in communication skills that enable them to offer the needed care. In a training effort by Stevens-Roseman and Leung (2004), caregivers

at a dementia center were taught communication techniques for active listening, managing older adults with memory loss and pain and helping residents express non-verbal cues. Similarly, a program called FOCUSED trained LTC caregivers in verbal and non-verbal communication techniques, using touch and eye contact as means of non-verbal cues, repeating nouns not pronouns, and reminding the conversation topic throughout the discussion (Ripich, Wykle, and Niles, 1995). A one-on-one communication skills program in a dementia home trained caregivers in popular techniques such as “addressing the resident by name”, “give short and clear instructions”, and “talk about resident’s life or day” (Bourgeois, Dijkstra, Burgio, and Allen, 2003). Other effective communication techniques suggested were the use of yes/no questions or reduced background noise during conversations while ineffective techniques that ‘disabled communication’ included ignoring or interrupting, speaking on behalf of the person, using complex or technical language or ‘talking out of ear shot’ (McCallion, Toseland, Lacye, and Banks, 1999; Allan & Killick, 2008). In addition to verbal and non-verbal communication with residents, frequent written communication and documentation of resident behaviors and moods were also found to facilitate information exchange and person-centered care (Kolanowski et al., 2015).

Care provider training in communication skills results in positive beliefs about older adults and aging amongst staff, increases knowledge of communication methods, reduces staff turnover, and improves interactive skills (McCallion et al., 1999; Steven-Roseman & Leung, 2004). Kolanowski and colleagues (2015) noted that nursing assistants in their research study called for educational training programs to be concise, visually appealing and timed at non-work hours. In focus groups, the direct care workers emphasized the importance of employing visual methods of learning versus written information available through the Internet or other modes. Educational and training sessions held “in between the press of care delivery” had greater chances of attentive learning and implementation (Kolanowski, Haitsma, Penrod, Hill & Yevchak, 2015). More importantly, training helped the care staff realize that ‘challenging’ behaviors often signal a gap in unmet needs (Algase et al., 1996).

Passalacqua & Harwood (2012) organized training for caregivers explicitly based on the person-centered dementia care guidelines called VIPS – a model proposed by Brooker (2004) and discussed earlier in this paper. Post-intervention, caregivers showed signs of optimism for people living with dementia, increased empathy for the residents, decreased depersonalization of residents i.e. treating them as “cases”, implemented new communication techniques reflecting a person-centered approach and spent more time on leisure activities with care

recipients (Passalacqua & Harwood, 2012). Mast (2013) emphasized the need for staff to be trained in identifying the individual strengths and non-cognitive abilities of people with dementia, instead of deficits or losses. Heid-Grubman (2013) also emphasized staff to be knowledgeable of short and long-term difficulties of people with dementia. Training that enables care providers to identify life histories and unique characteristics of residents also aids in person-centered care (Heid-Grubman, 2013). In addition, training carers to maintain comprehensive care plans and facilitate care transfers of residents efficiently also promotes person-centered care (Heid-Grubman, 2013). Having said that, staff training and educational programs have shown moderate benefits to improve quality of dementia care (Cohen-Mansfield, 2001). There is lack of evidence to confirm improvements in resident behavioral outcomes or quality of life ratings through these training programs (Beer et al., 2011; McCabe, Davison, & George, 2007).

In addition to staff training and communication skills, administrative support and direct-care staff empowerment is also important in facilitating person-centered care in LTC. Frontline workers feel more empowered when they are trained to work in challenging situations in assisting families, have supervisory help in the work during stressful times, are empowered to speak on behalf of residents and peers, and are equal partners in the processes and organizational structure of the facility (White-Chu et al., 2009). Developing leadership skills of Registered Nurses (RNs) in long term care facilities has also been recognized as an effective approach to improve quality of care and positive resident outcomes i.e. facilitate person-centered care (Scott-Cawiezell et al., 2006; Vogelsmeier, Farrah, Roam, & Ott, 2010).

Person-centered care can also be enhanced by training care providers to establish a strong relationship with not just residents, but also their families and loved ones, facilitating teamwork and supportive relationships (Viau-Guay et al., 2013). In a study to explore the staff characteristics valuable to family members in long-term care, Gladstone & Wexler (2000) found this relationship to be advantageous. Families value the care and attention staff give to the residents and family members, the partaking of information and opportunities for joint-problem solving and family engagement in caring for the residents (Galdstone & Wexler, 2000). To facilitate family collaboration and engagement in caregiving, staff and frontline workers can possibly: take the time to interact with family members, answer questions comprehensively, validate family queries, concerns and decisions, inform families of ongoing care issues and resolutions, inquire how families would like to be involved in care, acknowledge and appreciate the continuous family support received, engage families in problem-solving, listen and respond

to suggestions, and practice conflict resolution with a focus on problem solving and not managing personalities (Galdstone & Wexler, 2000).

Typically, LTC administrators and managers are sources of expertise and problem-solving outlets in residential care. Resident preferences and values are predicted and outlined through organizational policies and procedures, with little provision for spontaneity and resident choices (Corazzini & Anderson, 2014). The above findings reemphasize the need for rigorous staff training especially when caring for persons with dementia as “direct-care workers are often put in situations that require unusually sophisticated interpersonal and communication skills” (CEAL, 2010, p.18). Training staff in “adaptive leadership” techniques can be useful in dealing with *adaptive challenges* i.e. unpredictable types of problems with no present solutions, which cannot be resolved using technical expertise only (Heifetz, Linsky, & Grashow, 2009; Thygeson, Morrissey, & Ulstad, 2010). For example, to develop a person-centered solution to accommodate a resident’s choice of bath times, in the midst of staffing mix, shift changes, and staff availability, direct workers should be equipped to generate prompt individualized solutions to meet the residents’ needs (Corazzini & Anderson, 2014). This is a classic case of adaptive challenges encountered regularly in long term care facilities, with no solution available in the comprehensive policies and procedures of the organization. It is essential for LTC administrators and directors to rethink the mechanical way in which care is identified and provided in LTC, and support direct care workers to collaborate with residents and families to overcome adaptive challenges and essentially facilitate person-centered care.

3.3.1.3 Environmental Design

Neuroscience suggests that individuals have certain “hardwired” cognitive skills intact, despite dementia, which can be optimized through effective design and the physical environment (Zeisel, 2003). Powell Lawton, a renowned environmental gerontologist, whose work from the 1970s has been a prodigious contributor to purpose-built housing design for older adults emphasized the role of environmental options for the enrichment of older adult residents (Regnier, 2003). Lawton’s “environmental press model” (Lawton & Nahemow, 1973) highlights the correlation between a person’s abilities and the environment’s role for an optimized fit (Regnier, 2003). “Environment press” is defined as “forces in the environment that together with an individual need evoke a response”. The model indicates that vulnerable individuals with lower competencies are more susceptible to environmental press and may display maladaptive behavior in challenging situations (Chaudhary & Cooke, 2014). A person-environment fit occurs

when the demands and opportunities of a person's environment meet the capacity and abilities of the person. In later life, older adults with dementia need more variability and support from the environment for their various needs; therefore, the environment ought to be able to accommodate for a range of different situations (Regnier, 2003), especially in long term care homes. A person-environment misfit occurs when the demands of the environment exceed the abilities and capabilities of a person and hinders their adaptability for a comfortable life.

Environmental design in LTC aims to accomplish person-centered care by adapting the environment to enable people with dementia to maintain their sense of self and sustain meaningful relationships with other residents and caregivers (Day, Carreon, & Stump, 2000; Zeisel, 2003). Environmental design also serves as intervention for common BPSD symptoms such as agitation, aggression, social withdrawal and depression, promoting well-being and independence within people with dementia (Day et al., 2000; Zeisel et al., 2003). There is extensive literature on design guides and implementation in dementia care settings, which is beyond the scope of this literature review. However, it is important to note certain basic design features that facilitate person-centered care and serve as therapeutic tools in guiding behaviour for people with dementia.

The ultimate goal for effective environmental design is to foster independence and a sense of belonging for those living in residential care. Zeisel (2013) recommends eight types of design guidelines for long term care facilities to achieve this goal that defines person-centered care:

1. *'Controlled Exits Allow For Independence'*: designed exit doors do not invite elopement; instead a secure environment encourages meaningful movement and grants residents control of their surroundings. When 'prison guard' duties are removed from care providers, they are able to focus on the person and building person-centered relationships as an alternative to worrying about resident safety and security
2. *'Clear Walking Paths Clarify Destinations'*: curves, wandering loops and corners prevent meaningful walking, confuse people with dementia and prompt wandering. Walking paths made to outline landmarks or meaningful destinations encourage purposeful walking instead of aimless wandering, which boosts the residents' sense of place and purpose
3. *'Common Spaces: Room Purpose Indicators Improve Behaviour'*- developed common spaces like dining rooms, music rooms and other common spaces encourage resident participation, meaningful use of time, choice of space and appropriate behaviours. Meaningfully designed spaces prompt appropriate behaviour amongst people with dementia, and reduce their chances of being

- termed “sick”. This creates direct care workers and staff to treat residents as people first and people with a disability as second
4. *‘The Bedroom Needs To Be A Sanctuary’*- personalization and privacy in the bedroom gives residents a sense of control and feelings of homeliness. Having a “sense of self” stimulates residents to express their desires and wishes directly, instead of resorting to aggressive behaviours or impersonal ways
 5. *‘Gardens Must Be Safe and Easily Accessible’*- as previously mentioned; therapeutic outdoor spaces encourage residents’ free movement, in a guided and safe environment. Being in sunshine in the morning, aligns a person’s body clock and reduces evening “sundowning.” Outdoor access also allows residents to have a sense of time, place and seasons as well as provides continuity and familiarity with their previous rituals.
 6. *‘A Sense of Home Is Key To Comfort For Residents And Family’*- feelings of home can be achieved when room sizes mirror that of a real home and not an institution, and where residents can bring their own furniture, memorabilia and fixture. Staff can also probe a sense of home by normalizing the resident’s environment, behave and treat residents non-institutionally and encourage family participation. The more a resident is comfortable in their new home in residential care and is treated respectfully by care providers, the more opportunities occur for person-centered care and meaningful relationships
 7. *‘Residents Take Cues From Sensory Details They Comprehend’*- It is helpful if residents to receive coherent sensory messages from their surroundings to foster feelings of comfort and familiarity in long term care. When residents understand what they see, hear, smell and touch it increases their comprehension and matches the image they have maintained over their lifecourse
 8. *‘Supporting Independence Helps Retain It’*- environmental factors that support individuals to retain their abilities, like railings in hallways, high enough toilet seats to rise from unaided enable residents to stay independent without technological help. The more a person stays independent; it increases their sense of self and confidence and persuades their care providers to “treat the person as a person, not as a patient.”

(Zeisel, 2013, p. 46).

In addition to the person-centered design guidelines proposed by Zeisel (2013), there is abundant empirical literature on therapeutic design of environments for residents with dementia and its impact on the overall quality of life of these dwellers in long term care facilities (Chaudhary & Cooke, 2014; Day et al., 2000; Verbeek, van Rossum, Zwakhalen, Kempen, & Hamers, 2009). Size of unit for example, appears to matter. A study to assess the effect of small unit size households, over a one-year period, found dwellers to have fewer declines in

activities of daily living and less negative affects compared to those residents in traditional nursing homes (Reimer, Slaughter, Donaldson, Currie & Eliasziw, 2004). Funaki and colleagues found a significant improvement in the quality of life of residents that moved into a group-living home, and upon three months after, basing their findings on the level of household engagement. Other studies that examined the effects of small unit size on residents, found improvements in social engagement, greater positivity, improved functionality, higher quality of life scores, feelings of homeliness, sense of self and social connectedness, activity engagement, non-verbal social behaviors and less deterioration in cognitive functionality, compared to residents that live in large institutional facilities (de Rooij, Luijkx, Schaafsma, Declerca, Emmerink, & Schols, 2012; Kok, Heuvelen, Berg & Scherder, 2016; McFadden & Lunsman, 2010; Smith, Mathews, & Gresham, 2010; Suzuki, Kanamori, Yasuda, & Oshiro, 2008; te Boekhorst, Depla, de Lange, Pot, & Eefsting, 2009; Thistleton, Warmuth, & Joseph, 2012; Van Zadelhoff, Verbeek, Widdershoven, van Rossum, & Abma, 2011; Verbeek, Zwakhalen, van Rosum, Ambergen, Kempen, & Hamers, 2010).

Research on a more *home like* environmental design in care homes with open-plan lounge/dining/activity areas, personalized furniture, homelike floors, and warm and welcoming lighting has been found to have positive results on residents. Research suggests that these environments lead to decreased behavioral issues, lower levels of verbal and overall aggression, anxiety and agitation, fewer and infrequent incidents of pacing and walking, and longer periods of sitting amongst residents (Garcia et al., 2012; Wilkes, Fleming, Wilkes, Cioffi & Le Miere, 2005; Yao & Algase, 2006; Zeisel et al., 2003). Homelike characters in common spaces of the care facilities have also shown decrease in social withdrawals and increased social participation amongst residents (Zeisel et al., 2003).

Empirical evidence stresses the importance of spatial layout, orientation cues and sensory stimulation as contributing factors to therapeutic person-centered care. Group size units with and I-shaped corridor i.e. straight circulation systems increased way finding for residents with moderate to severe dementia compared to those units that were multi-directional (Marquardt & Schmiege, 2009). Passini and colleagues (2000) learned that furniture and large floor numbers on the wall were useful for residents to independently navigate their way around. Other orientation cues that helped residents find their rooms were photographs of themselves, memorabilia items and residents' name in large font size (Nolan, Mathews, & Harrison, 2001; Nolan, Mathews, Truesdell-Todd & Van Dorp, 2002).

Several studies assess the sensory stimulation in long-term care facilities and its impact on the quality of life of the residents. Research suggests that noise levels (alarms, intercoms, phones, loud staff conversations, television and equipment etc.) in residential care homes often exceed the recommended levels for residential dwellings (Bharathan et al., 2007; Garre-Olmo et al., 2012; Joosse, 2011; World Health Organization, 1999). Increased noise levels are associated with lower social interactions, behavioral and disruptive issues like agitation and aggression as well as increased wandering amongst the residents (Algase, Elizabeth, Beattie, Beel-Bates, & Yao, 2010; Campo & Chaudhury, 2012; Garcia et al, 2012; Garre-Olmo et al., 2012; Joosse, 2012). In addition to noise, evidence also indicates that residents spend most of their time in dim lights and are commonly exposed to lower lighting than recommended, which affects their overall well-being (De Lepeleire, Bouwen, De Coninck, & Buntinx, 2007; Garre-Olmo et al., 2012; Schochat, Martin, Marler, & Ancoli-Israel, 2000). If exposed to brighter light, residents can improve their circadian rhythm quality which would help their daytime wakefulness and night-time sleep, increase total sleep duration, lower functional deterioration, reduce restlessness, have better mood and lesser instances of agitated and aggressive behaviors (Ancoli-Israel et al, 2003; Dowling, Graf, Hubbard & Luxenberg, 2007; Fetveit & Bjorvatn, 2005; Graf et al., 2001; Nowak & Davis, 2011; Riemersma-van der Lek et al., 2008; Sloane et al., 2007; Thorpe, Middleton, Russell, & Stewart, 2000; van Hoof, Aarts, Rense & Schouten, 2009). Chaudhary & Cooke (2014) suggest that facilities increase ambient light levels in common areas where residents spend of their time, as efforts to maximize the benefits of it.

Certainly, the environmental design in care homes has a significant role in boosting the quality of life of the residents. That said, Lawton (1975) highlights the transactional relationship between design and management. Merely, a skilfully designed environment is not sufficient for impact, but should be supported by qualified management and leadership for effective results (Regnier, 2003). While technical skills can always be taught to newly hired staff in long-term care, effective managers must innately possess a sentimental attachment and passion to gratify the residents to deliver remarkable care (Regnier, 2003). Impactful leadership, sensitive care providers and effective environmental designs are all contributing factors in facilitating person-centered care with optimal outcomes for the residents.

3.3.2 Organizational Barriers for Implementing Person-Centered Care

The preceding sections of this review discussed the facilitators of implementing person-centered care to residents in long term-care facilities. Despite its manifold benefits on the overall well-being and quality of life of residents, as well as its effect on the quality of care delivered by staff, this care approach faces multiple barriers in implementation. This section will focus on the *structural, environmental and other (financial and personal) barriers* to implementing person-centered care in LTC.

3.3.2.1 Structural Barriers

Research indicates many barriers in implementing culture change and a person-centered approach to care in residential facilities. Time constraints and staffing models in traditional models of care limit meaningful interactions between staff and residents and restrict response time to manage behavioural issues due to competing demands (Kolanowski et al., 2015). In a qualitative study to assess barriers to implementing person-centered care, Rockwell (2012) found staff workload to be an impediment: one care aide was responsible for six to seven residents per shift, restricting relationship building and individualized attention to the residents' needs. Inadequate staff patterns especially for the evening and night shifts further neglect 24-hour person-centered care in LTC (Kolanowski, Fick, Frazer, & Penrod, 2015).

The biomedical care approach typically undermines the importance of social and emotional care and minimally employs allied health disciplinarians in occupational therapy, physiotherapy, rehabilitation therapy, activity programming and music therapy (Bonifas, 2011; Rockwell, 2012). This consequently increases workload for other care staff in the facilities. It is not uncommon for one or two social workers to be employed to manage up to a 100 to 221 residents in LTC, jeopardizing the quality of care delivered (Rockwell, 2012). Limited access to behavioural health professionals such as psychologists and advanced practice nurses also restrict evidence-based behavioural responses to BPSD in residents (Kolanowski et al., 2015) and potentially risk the use of pharmacological intervention.

Communication amongst direct-care workers and access to resident information are also cited as structural barriers in directing person-centered care (Kolanowski et al., 2015). Lack of communication between staff and administrative leaders, amongst staff members, and staff and

residents were all cited as potential obstacles (Norton, 2010). In a study to assess communication as a barrier, staff alluded to two types of information essential to delivering PCC to residents, a) information about the person and his/her life, and b) information on useful educational approaches to resident behaviours (Kolanowski et al., 2015). The lack of availability of personal information of residents and limited verbal and written information exchange between direct-care workers impedes the PCC process (Kolanowski et al., 2015; Vikstrom et al., 2015). Caspar (2014) found written care-related information in selected organizations to be reliant on job classification. This restricted residential care aides, who were responsible for 80% of care to residents, to access the important information relevant to their residents (Caspar, 2014). Most information exchange amongst direct care workers, i.e. the care aides was done orally, and heavily relied on the care aides' conversational abilities and working relationships with one another (Caspar, 2014). Alternatively, in case where information exchange is documented, it's time-consuming and the quality is inconsistent varying from shift to shift, unhelpful to those new to the care facility (Kolowski et al., 2015). For residents with dementia, lack of family involvement to provide caregivers with information on resident life histories, preferences, likes/dislikes, and routines are also described as obstacles in integrating PCC interventions into practice (Vikstorm et al., 2015). Furthermore, the lack of multidirectional relationships between staff and residents in LTC, being compromised to the traditional unidirectional relationships of staff to residents, also hinder affection and mutual benefits of care to all parties (Rockwell, 2012).

Other notable structural barriers cited in long term care, contrary to the values of person-centered care, are compliance with state regulations, conventional regulations around food services and liability issues, prioritizing health and safety over resident choices, stringent admission to facilities, levels of care, transfers within facilities, structural limitations within the community and systemic barriers like compliance with state regulations and unions (Norton, 2010; Rockwell, 2012).

3.3.2.2 Environmental Barriers

Environmental barriers of implementing PCC are rooted in the historic position of long-term care in the health care system, and its conformity to the regulations, funding and policies shaped by the medical model of care (Rockwell, 2012). Rockwell's (2012) findings indicate that typically, long term care facilities are affiliated with hospitals or rehabilitation centers, possessed by long, dull hallways, multi-bed ward rooms, strict care routines, limited staffing structure and

military meal plans. The relocation of older adults from their community homes to long-term care i.e. “permanent hospitals” strips them from privacy, independence and opportunities for choice. Other environmental barriers are noticed in the limited spaces available for multiple, simultaneous activities: one large open room is often the venue of recreational, social, spiritual, physical and functional activities. Findings also express staff’s discontentment with their daily struggle to make the residential care environment more “home-like” for the residents to feel comfortable. Limited private visiting areas and lack of friendly furniture exacerbate the situation (Rockwell, 2012).

Traditional environmental designs of residential care are an obstruction to implementing person-centered care. The physical space is often not favourable to the household or neighborhood model (Norton, 2010). Heid and colleagues (2014) reported some environments that obstruct person-centered care for the residents; facility schedules regarding care, timings and staff schedules (i.e. offering residents a designated time of the week to bathe), facility policies (i.e. no pets allowed), physical environment restrictions (i.e. unable to move certain pieces of furniture, facility policies around belongings and facility resources (i.e. not enough transportation options). The built environment impedes one-on-one communication amongst staff and residents, further aggravated by rigorous staffing models, lack of person-centered care training, heavy workload and top-down management structures.

3.3.2.3 Personal and Financial barriers

The greatest challenge in attempting culture change is recognized in the organization, staff and residents’ resistance to change and its rooted belief in the institutionalized model of care (Norton, 2010; Rockwell, 2012; Sampsell, 2003; Viau-Guay et al., 2012). Robinson & Rosher (2006) report the facility’s hesitation to reorganize decision making i.e. enabling frontline care staff to make decisions for the residents. Despite the leadership’s understanding of the culture change model, and the dire need to present decision-making opportunities to front-line workers, this hierarchical transformation is a clear *personal barrier* within the organization. Administrators’ and directors’ role as decision-makers in their life-long careers pose challenge for inverting the organizational structure to give decision-making power to front-like workers (Robinson & Rosher, 2006). Even when self-directed teams are implemented, often those closest to the residents have difficulty making decisions (Robinson & Rosher, 2006). While giving up control to flatten the management structure is difficult, ongoing education for administrators and direct care workers may be useful to decentralize the organization style and

instill culture change (Robinson & Rosher, 2006). However, educational training may also face *personal* barriers in implementation. Computer literacy is often cited as a barrier to online training for care staff (Hobday, Savik, Smith and Gaugler, 2010). Others have cited some front-line workers to be more responsive to experiential learning as opposed to traditional lecture style learning (Kemeny, Boettcher, DeShon, & Stevens, 2006). Vikstrom and colleagues (2015) suggest in order to implement a bottom-up approach and overcome staff educational/learning barriers, organizations should encourage staff to learn at their own pace on their own terms. By giving staff the ownership over the culture change process and the implementation of person-centered care, many personal barriers can be weakened.

The structural and environmental barriers are further exacerbated by inadequate funding or financial reimbursements at long term care facilities. These *financial* barriers limit the organization's ability to deliver person-centered care to the residents. Due to funding constraints organizations are often unable to manage the cost of changing infrastructure to overcome the environmental barriers. Anecdotal evidence also indicates that financial barriers restrict organizations to hire more staff from varied healthcare disciplines to provide person-centered direct care to the residents. To counter this, a practice in the United States suggests that the regime of Medicaid pay for performance regulations has promoted culture change (Miller, Cohen, Lima, & Mor, 2014). Reimbursement regulations or financial funds that advocate for greater staffing levels and environmental changes endorse person-centered care in LTC and promote a real culture change to occur (Kolawski et al., 2015).

3.3.3 Benefits of Person-centered care Implementation

Transforming care from a medical model to a more person-centered approach provides opportunity to improve quality of life of residents and quality of care provided by care givers (Norton, 2010). Several studies indicate the benefits of the implementation of person-centered care amongst care staff and care recipients, and will be discussed in this section.

3.3.3.1 Care Providers

The long-term care industry struggles to attract and retain competent and trained care workers due to the demanding work conditions, negative perceptions of caring for the aged and the expected labor shortages in this market (Vernooij-Dassen et al., 2009). A study to measure the impact of person-centered care approach on care staff in long term care resulted in greater job satisfaction amongst the direct care workers (Edvardsson, Fetherstonhaugh, McAuliffe, Nay & Chenco, 2011). Person-centered care approach allows care staff to provide personalized and direct care and find interventions for challenging situations- key indicators in influencing job satisfaction (Edvardsson et al., 2011; van Weert et al., 2005). Other factors in a person-centered care environment linked to positive job satisfaction amongst care staff include: a positive psychosocial environment, power of decision-making in providing care, availability of clinical supervision and organizational support (Berg, Welander-Hansson & Hallberg, 1994; Ryan et al., 2004).

Nolan and colleagues (2004) stated therapeutic environments and supportive organization culture enabled care staff to provide good care therefore increasing their job satisfaction and sense of achievement. Boekhorst and colleagues (2008) examined the wellbeing of care staff in group-living homes versus large nursing facilities for people with dementia. Results indicated higher job satisfaction and lower burnout amongst nursing staff in group-living, due to more social support from colleagues and management, greater control and fewer stresses (Boekherst et al., 2008). In addition to the previously discussed benefits to residents, small-scale and home-like nursing care models were also found to influence staff's perception of the work environment. Willemse, Depla, Smit & Pot (2014) reported small-scale homes increased staff decision authority and reduced job demands. Other studies indicated higher sense of accomplishment and reduced emotional exhaustion while providing personalized care, with lower rates of staff absenteeism (Berkhout et al., 2004; van Weert et al.,

2005). These findings indicate a positive effect of person-centered care model on the well-being of care staff which enforces the quality of care provided to the residents.

3.3.3.2 Care Recipients

The implementation of person-centered care in long term care facilities has resulted in significant outcomes for the residents. Applying the Eden Alternative in LTC increased self-care amongst the residents and significantly affected helplessness and boredom amongst residents (Brownie & Nancarrow, 2012; Sampsell, 2003). Kane and colleagues (2007) reported a better-perceived quality of life amongst residents in a Greenhouse facility: the residents were satisfied with the quality of care received and the standard of living in a Greenhouse model. A randomized controlled trial to compare the effects of person-centered care, dementia care mapping and usual care yielded results indicated that the two former methods reduced agitation in people with dementia in LTC (Chenoweth et al., 2003). Effective environmental design to reinforce personhood amongst residents increased independence, privacy and autonomy amongst people with dementia (Zeisel, 2013). In another study, Zeisel and colleagues evaluated the impact of design elements on the behaviors of people with dementia- the results showed reduced incidents of depression, anxiety, aggression and social withdrawal amongst the residents (Zeisel et al., 2003). Other empirical evidence indicated the use of non-pharmaceutical interventions, effective communication techniques, prioritized resident needs over the organizations' and resident-staff relationships affected the overall well-being of residents in PCC facilities (Chenoweth et al., 2009; Fossey et al., 2006; Hoeffler, 2006; Sampsell, 2003)

Person centered care has also demonstrated to impact the residents' family satisfaction and participation in activities (Robinson & Rosher, 2006; Sampsell, 2003). Family members of residents at the Greenhouse facility expressed greater satisfaction in the physical environment, homelikeness of the facility, privacy and autonomy of residents and flexibility in meals, housekeeping and amenities (Lum, Kane, Cutler & Yu, 2009). The holistic facilitation of culture change, environmental design and dedicated direct care workers contributed to the overall quality of life and wellbeing for the residents living in their homes i.e. long term care facilities.

Chapter 4. Conceptual Framework

This conceptual framework has been developed as a tool to help visualize and understand the various factors that contribute to the implementation of person-centered care. A conceptual framework “lays out the key factors, constructs, or variables, and presumes relationships among them” (Miles & Huberman, 1994, p. 440). Developing a conceptual framework is valuable as it provides an “interpretative approach to social reality” and provides a comprehensive understanding of various complex phenomenon (Jabareen, 2009). The results of this literature review are presented in this conceptual framework that contemplates the association between the organizational facilitators and barriers in implementing person-centered care in long-term care.

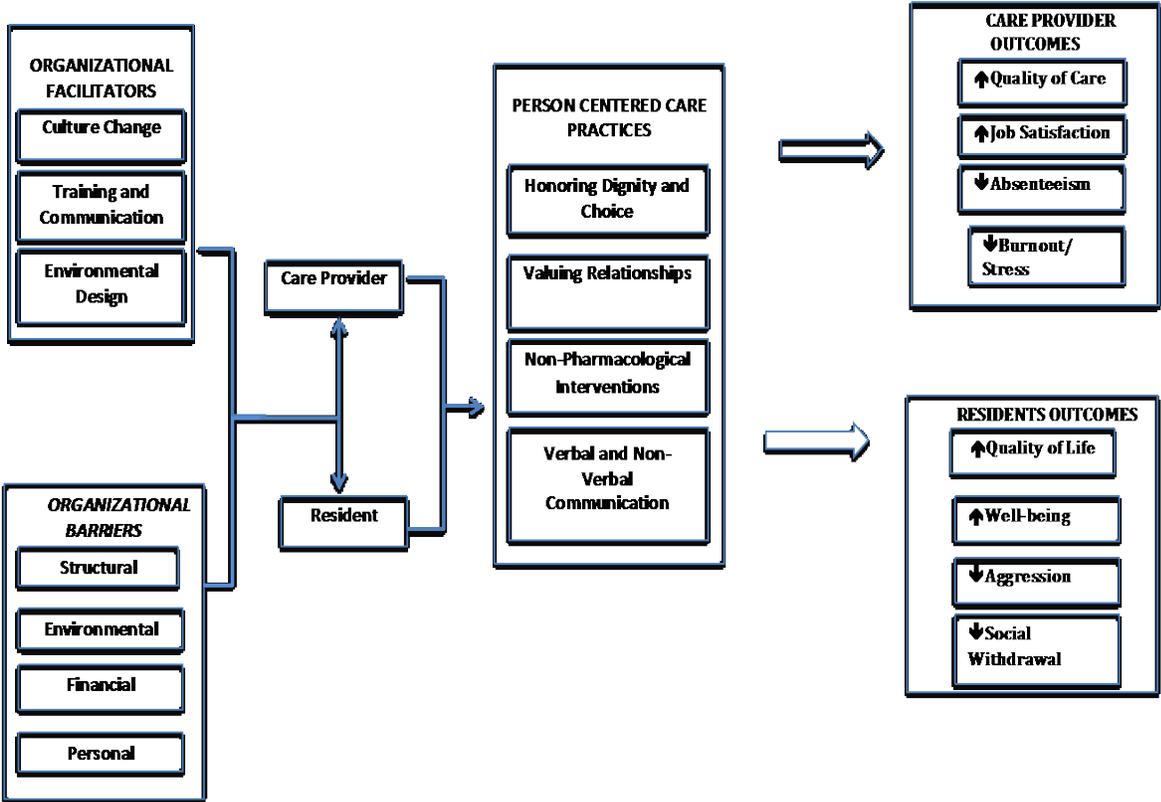


Figure 1: Organizational facilitators and barriers that influence implementation of person-centered care practices in long-term care facilities

The framework is guided by the concepts identified in this literature review and is informed by Brooker's (2004) work on the four essential elements i.e. VIPs and their role in providing person-centered care to older adults. Promoting a person-centered care approach requires a culture change initiative in long-term care that values the holistic needs of its residents. Implementation of person –centered care also lies in the organization's ability to identify residents' individual preferences and life histories, and empower them in decision-making including people who have dementia. Along with this acknowledgement, there would be expectations regarding the management's initiatives to train its care staff adequately, adopt a decentralized team method of care delivery, and enable them to make independent decisions while providing direct care. Person-centered care strongly relies on a committed and informed leadership team who exemplifies this care approach, instills it in the organizational philosophy and vision, and models behaviours expected of staff in their interactions with residents. The leaders or culture change initiators promote culture change, empower and direct care workers and staff in collaborative decision-making working as a team to also facilitate relationship-centred care practices.

Implementation of person centered care practices needs the support of appropriate organizational structure, supportive staff culture, appropriately trained staff and a responsive physical environment. The critical role of direct care providers is heightened during the implementation process of person-centered care. Staff training and education on care practices and relational communication enables appropriate responses to unmet needs, behavioural conflicts and personalized attention to residents. Person-centered care depends on the staff's understanding, 'buy-in', commitment and implementation of this philosophy in its care. Effective staff training equips the direct care workers to provide individualized care that adopts each resident's preferences, likes, skills and habits. This flexible care allows staff to spend quality time with the residents with mutual benefits of friendship, laughter, support and learning. When staff and care aides closest to the residents are aware of the residents' preferences and history, it empowers them to make decisions most suited and appropriate to each individual. Giving the front line staff the voice and opportunity to make decisions on their own and be creative in the field boosts job satisfaction as well as fosters a meaningful relationship between the staff, residents and families. Along with staff training, administrative leaders must make continuity of care their standard to delivering quality care. Sufficient staffing levels and continuity of care facilitate direct workers to use their knowledge to better meet the needs of the residents and maintain trusting relationships with each other. Ongoing staff training programs and professional

education keeps them updated with best practices, opportunities for peer discussion and knowledge transfer, as well as the platform to address the troubles and challenges witnessed on the job. Collectively, these initiatives aim to value and empower staff to believe in person-centered care and adopt this philosophy to enrich the lives of the residents.

While staff training, education and teamwork are important contributors to individualized care, the role of responsive physical environmental features of the care setting cannot be discounted. Traditionally structured, hospital like care facilities obscures the features of homelikeness, therapeutic interventions, access to outdoor settings and most importantly, opportunities for informal social interactions for the residents and staff. If not deterred, certain aspects of institutionalized environments like large communal spaces for activities, multi-occupancy bedrooms, institutional dining areas, mass-produced meal plans and stringent schedules can continue to harness the freedom, choice and dignity of the residents. Accessible physical environments that promote the residents' mobility, freedom, choices and opportunities for spontaneity encourage person-centered care. Small homes allow residents to maintain their privacy, provide space for intimate relationships, and incorporate homelike routines and rituals that reflect the true identity of the residents.

Environmental design can play a prominent role in delivering person-centered care. For example, let us consider mealtimes at a long term care facility with double-occupancy resident rooms, long corridors and a large common dining room. For all residents to make it to the dining room in time, care aides most likely have to start directing/wheeling the more dependent residents (with or without consent) to the dining room much prior to the actual mealtime, with many residents waiting around for as much as an hour before the meal is served. The inconvenience of the environmental design not only devalues the time of the residents - indicating residents have nothing more meaningful to do then wait for a meal - it also causes behavioral issues during the waiting period, humiliates resident dignity and preference of coming to the dining room when the meal is ready, increases pressure on care staff to plan ahead of time, and deciphers a joyous, sociable mealtime to a mere task. Given the same scenario in a small home environment with private dining areas for 8-10 dwellers, residents would be at liberty to come in and leave as per their choice, engage in social interaction if interested, or choose to stay in their rooms if not hungry. Thus, the environmental design along with well-trained staff and the culture change initiative unanimously facilitate person-centered care practices in long-term care.

Although the influential factors revolutionize a shift in organization practices, certain organizational barriers interrupt the process of delivering person-centered care. Structural barriers such as large sized facilities and training issues are impacted by financial (funding) restrictions that effect the organization's training or redesigning objectives. Other barriers such as compliance to policies and regulations adhered to the medical model of care, limits the organizations will and capacity to adopt this care approach. The management's personal limitations and resistance to change, and the ingrained belief in the bio-medical approach to provide care further exacerbate these barriers. These barriers restrict the leadership, administration, staff, families and residents to cohesively participate in a person-centered care environment. The barriers instigate the task-focused model of care, to meet the medical needs of the residents, and forfeit the primary goal of response to psychosocial needs and the preservation of personhood.

As the framework indicates, the facilitators and barriers collaboratively influence the relationship between the care provider and the residents. The facilitators, if manifested efficiently, and the barriers, if impeded, provide opportunities for staff to employ quality time to the residents. This also provides opportunity for the care provider and staff to experience a set of senses, as promoted by the relational care model. Person-centered care is more likely to occur once the individuals mutually foresee the benefits of the caregiving process. Person-centered care practices are catered to meet the residents' needs to honor their dignity and choices. These care practices recognize the residents' abilities, preferences and focus on care that optimizes their well-being and quality of life. Choices and options to preferred meal times, bath times, socialization, and meaningful activity engagement exemplify this care approach. The care delivery process focuses on the residents' retained abilities and what they are able to accomplish in their current state of being. Especially for people with dementia, care practices necessitate respectful verbal and non-verbal communication and non-pharmacological interventions to mitigate any deficiencies as a result of the disease. Person-centered care practices are the intermediary outcomes necessary to accomplish the end outcome or the objective of the organization.

An organizational culture that encourages person-centered care practices by supporting its care staff and valuing the needs of its residents subsequently creates an environment beneficial to the care staff and the residents. Person-centered care increases job satisfaction and improves quality of care amongst the care staff, while reducing burnout, stress and absenteeism (Sampsell, 2003). Person-centered care approach also yields multiple benefits for

the residents. Research confirms that it improves the well-being and quality of life of the residents, as well as reduces incidents of aggression, anxiety and social exclusion (Chenoweth et al., 2009; Fossey, 2006; Sloane et al., 2004; Sidani, Streiner & Leclerc, 2012). The residents gain from person-centered care that epitomizes dignity and choice and the organizational facilitators that initiate and adopt change. These outcomes collectively lead to the goal to preserve and maintain the personhood of the individuals in their new home. Interestingly, the three levels of personhood i.e. biological, individual and sociological (Buron, 2008) resonate through the influential factors and intermediate outcomes. In essence, the organization as a team works to maintain biological personhood by recognizing the resident's ability to experience gratification and pain (Moody, 2003); individual personhood by creating self-awareness, strengthening personal and social relationships and encouraging different types of verbal and non-verbal communication; and sociological personhood by mitigating the challenges of social isolation and stigmatization through meaningful engagement and appreciation, and increasing mobility and way finding through effective environmental design. This conceptual framework emphasizes on the role of organizational facilitators and barriers that influence the implementation of person-centered care practices and affect the overall objective of preserving personhood of the residents. However, this conceptual framework would need to be contextualized to meet the cultural variability i.e. the cultural beliefs, values, concepts and languages of different organizations.

Chapter 5. Discussion

5.1 Critical Summary of Evidence

This review synthesizes existing literature on person-centered care, with a focus on care practices and organizational issues. The review concentrates on a needs-based model of care, dissecting the critical demands of a person in the care process. The essence of this literature review is based on the diagnosis that “challenging” behaviours in people with dementia are a consequence of unmet needs and quality of the care received (Brooker, 2004). Based on this, the review dwells on the overarching needs of the person, specific needs of people with dementia and its compensating care, the connection between the needs and delivery of care and the organization’s role in this process. The first chapter draws attention to the individual characteristics of being human. McCormack’s (2004) explanation of the ‘second-order reflection’ supports the understanding that individuals in later years make life decisions based on the guiding principles and preferences accumulated throughout the life course, to live a life they desire. This analysis promotes the protection of one’s personhood i.e. the status bestowed to individuals through relationships and social networks (Kitwood, 1997). However, individuals face challenges in maintaining their sense of personhood when living with dementia and/or living in long term care facilities in later years. And it is this treatment of others that can result in at least some of the functional deterioration and problematic behaviours that are often blamed on the ‘disease’ process.

A key strength of this review is that it establishes a clearer understanding of the social ‘needs’ of people with dementia and associated appropriate care. Evidence confirms that unmet needs range from limited social support, lack of stimulated activities and meaningful engagement to restricted necessities like choices in wake time and bath time. Person-centered care goes beyond meeting the care needs of recipients in the medical domain or improving the health care outcomes; it understands the person as a whole (Kitwood, 1997). Person-centered care embraces care receivers as partners, collaborators and active stakeholders in the caregiving process. As this literature review indicates, person-centered, relationship-based, individualized care approaches positively impact the lives of care recipients to preserve their personhood, preferences, dignity and choices. Another strength of this review is that it connects the holistic individualistic needs of ‘persons’ in long-term care facilities to the care practices most suited for the preservation of their personhood.

Brooker's (2004) contemporary definition of person-centered care and the 'VIPS' approach to care is beneficial for everyone, especially for those with dementia, no matter where they live or what intact abilities they retain. In response to these guiding principles, this review discusses some evidence-based care strategies useful in a long-term care environment. Organizations that recognize the residents' as persons with abilities to make choices for themselves in the context of their retained abilities, their freedom to think and feel despite their cognitive and functional losses, their inherent dignity and personal needs, their value to the society and their purpose of living are best suited to model a person-centered care approach.

In the discussion to preserve the personhood of residents in long-term care, the term "social death" (Glaser and Strauss, 1966) emerges as a concern. People with dementia are often subject to dehumanized and stigmatized behavior that disregards their personhood and results in a social death in the society long before their physical death (Sweeting & Gilhooly, 1997). Professional caregivers can overcome this by modeling inclusionary care practices that recognize the abilities and respect the personhood of people with dementia. When care staff participate in person-centered care, cultivate meaningful relationships with residents and respond to verbal and non-verbal communication, the 'task' of physical care is seconded to the psychosocial needs of the living person. As an extension to person-centered care, relationship-centered care strives to improve the socio-emotional wellbeing of residents by building strong and meaningful interpersonal relationships, mutual benefits of care to everyone and inclusion of family and the wider community in the lives of the residents (Rockwell, 2012). This didactic interactive care approach recognizes that to provide person-centered care, one must feel like 'person' within the organization, that to provide good care, one must also feel cared for. This is the foundation of relationship centered care.

Person-centered care prescribes non-pharmacological care to combat the behavioral and psychological symptoms of dementia (BPSD) because the behavior is seen not as a symptom of the disease but as an emotional reaction to the 'dysfunctional social treatment by the 'healthy others'. Creative expressions such as music and art therapy, reminiscence therapy, multisensory stimulation (MSSE) promote self-expression and meaningful occupation in individuals often juggling with the nuances of age, multimorbidity, relocation and isolation. When long-term care programs, such as the Eden Alternative facilities or others promoting more person-centred approaches, focus for example, on therapeutic interventions to increase social engagement and reduce boredom and loneliness the dependence on antipsychotic medication is reduced and the psychosocial desires of the residents can be fulfilled.

Although the needs of the residents are identified and the necessity of compensating care is reinforced through staff interactions, communications and therapeutic care, much of the culture change revolution is at the discretion of the organization. A significant outcome of this study is that it connects the organizational issues with care practices. Chapter 3 focuses on the vital factors of the culture change movement and the role of leadership and long-term care administrators in this process. The success of visionary care models such as the Eden Alternative, the Greenhouse Project, the Pioneer Network emphasize on leadership commitment and care staff empowerment to be central to facilitate person-centered care. Organizational facilitators such as adequate staff training in adaptive leadership, problem solving and communication tactics as well as therapeutic environmental design enable residents to optimize abilities and enhance their quality of life in long-term care. Conversely, structural, environmental and financial barriers in the organization impede the execution of person-centered care. Time constraints and staffing models often depict the traditional model of care limiting meaningful interactions between care staff, residents and families. Inadequate access to essential resident information, minimal allied health disciplinarians, compliance with rigorous staff regulations and health and safety issues are all cited as structural barriers in long term care. Additionally, environmental barriers such as reliance on biomedical care, conventional, hospital like facility restrictions, top-down management structure and stringent policies obstruct person-centered training and care. Personal and financial barriers like resistance to change and limited funds for advancement also deter real culture change in long term care organizations. Therefore, this study concludes that effective implementation of person-centered care in LTC is achievable when the leadership and management demonstrate confidence in the team's ability to meet the goals for culture change and commits to overcoming the barriers, with transformation that reflects in the quality of care and quality of life of the residents (Rosemand, Hanson, Ennett, Schenck, & Weiner, 2011).

The present study connects the organizational issues and care practices in the efforts to address the unmet needs of people with dementia in a long term care setting. The results of this review should be interpreted with the following limitations. A universal definition of person-centered care is missing in clinical gerontology, which limits researchers and practitioners to articulate what is meant by it and influence the prospective agenda (Brooker, 2004; Li & Porock, 2014). As the selection criteria of articles included in this study was limited to a selection of key terms, comparable studies may have been overlooked that could have added value to this study. Additionally, only articles that explicitly addressed person-centered care for people with

dementia in long term care facilities were included. Given the focused selection criterion for this review, articles that discuss person-centered care practices in diverse settings such as hospitals and palliative care may have been omitted.

A few methodological limitations can be noted about the studies included in this review. Many studies cite small sample size to be a limitation. While small sample size is common in studies focused on older adults (Tang & Brown, 2006), it questions the generalizability and representation of the findings to the institutionalized cohort. In addition to limited small sample sizes, several studies employed a cross sectional design for analysis. Although the studies did yield promising results, longitudinal studies would be more beneficial to appreciate the long term effects of person-centered care practices in improving the lives of the residents in long term care facilities. Most studies did not have comparison groups to validate the results of implementing person-centered care for residents and staff. While it may be difficult to include control groups given the vulnerability of the long-term care population, future studies that include a pre-test and post-test design may be helpful to determine the longer term impact of person-centered care on the residents.

The well-being of residents in long term care and consequently their quality of life is determined by multiple factors such as their physiological, psychological, behavioural, and social status (Li & Porock, 2014). The articles included in this study were limited to subjective measures i.e. the psychological and behavioural changes due to person-centered care practices. The inclusion of residents' physiological wellbeing such as the residents' sleep patterns, daytime wakefulness, functional status, mobility would help verify the effectiveness of person-centered care on the overall well-being of residents. The several research designs also represented either qualitative or quantitative data. The collection of both objective and subjective data i.e. mixed methods studies whenever feasible would yield more rigorous, systematic and validated results (Cushman & Rosenberg, 1991).

Although the current study did not initially focus on person-centered care for people with dementia, the juxtaposition of the two were evident in the literature. Given the association, articles in this study had to meet this criterion. However, several articles did not specify the level of cognitive impairment i.e. dementia in the participants of the study. Some studies focused on residents with early-stage dementia while most indicated participants to have some form of cognitive impairment. Presuming that people with advanced dementia could not have effectively participated in the studies, the outcomes restrict the generalizability of effectiveness of person-

centered care to the diverse institutionalized cohort. This also yields participant selection bias, with the 'fittest' of the most needful as subjects of evaluation. It restricts voices of the most in need as well as makes it difficult to develop sustainable PCC programs to meet the needs of different levels of resident abilities and impairments. Similarly, studies that evaluate staff satisfaction with PCC implementation, failed to record the process of participant selection leading to potential sample bias and unreliable results.

It is important to note that the scope of this literature did not include certain topics valuable in understanding the implementation and effectiveness of person-centered care in long-term care facilities. The physical environment is an essential component of therapeutic care for people with dementia (Chaudhary & Cooke, 2014). There is a large body of literature examining the effect of physical environment on behaviours in people with dementia such as reduced agitation, increased social participation and greater independence, which was not extensively included. Similarly, this review did not deliberate on physical or recreational activities as sources of therapeutic care to address the unmet, psychosocial needs of residents with dementia. Future literature reviews would benefit from the inclusion of these topics to better understand the holistic gains of person-centered care and to develop recommendations and programs supported by empirical evidence. While the current study only reviewed the organizational barriers in the PCC process, future research would benefit from dwelling into these barriers with recommendations to overcome these obstacles.

The quality of care in residential facilities requires radical improvement to better address the needs of its residents, especially people with dementia (Ballard et al., 2001). While there is rich theoretical and conceptual literature on person-centered care, more empirical evidence is needed to validate these theoretical voices to stipulate practical resolutions. While some studies discuss facilities that implement person-centered care, there is a lack of studies on how organizations systematically plan for culture change, apply incremental changes and address the organizational barriers in the process. Some studies only adopt atomistic elements of person-centered care restricting the analysis of the overall impact. There is also limited data available on the effects of person-centered care on the operations of organizations, the long-term benefits of culture change, and ways to strengthen lifelong buy-in of care staff for PCC sustainment. Although relationship-centered care is cited as a barrier-free solution to person-centered care (Rockwell, 2012), there is a gap in the literature stimulating this discussion. Most notably, the inconsistency in the definition and interpretation of person-centered care, culture

change, and well-being in theory and health care systems limits the scope of this review and hampers access to all relevant information pertinent to the subject.

5.2 Future Research Directions

As the population rapidly ages in the coming years, it is vital for long-term care providers to incorporate the values and goals of person-centered care into practice. Although, PCC interventions may have good efficacy in theory, further research needs to testify its sustainability in real environments. For instance, evaluating the practical implications of using the VIPS model in training and sustainability of PCC would help confirm the theory into practice. Similarly, Kontos & Naglie (2007) identify the communicative capacity of the bodily expressions in the advanced stages of dementia and the need for further investigation on this outlet to provide insight on improved person-centered care. Rockwell (2012) recognizes the potential of relational care to compensate for the barriers in the current PCC agenda and future research is needed to examine the role of social workers in creating multidirectional relationships in care homes to validate this theory and expand the scope of care.

Most importantly, having a clear and consistent philosophy of person-centered care in homes for people with dementia is vital to encourage appropriate decision-making by staff and enhance the impact of this care approach on the residents (Willimse et al., 2014). Another area of study could be to explore the dynamics and relationships between management and care staff as well as the quality of relationships between staff and residents, to assess the versatility of PCC. Additionally, it would be useful to assess the viability of PCC in long-term care facilities for all residents, with or without dementia. Future studies should also aim to measure environmental safety in person-centered care facilities as an increased risk of falls in these facilities appear to be a possible outcome of PCC interventions (Brownie & Nancarrow, 2013).

This study is geared towards person-centered interventions to address unmet needs and improve psychosocial behaviours in people with dementia, however future studies that focus on quality of life indicators would contribute significantly to this topic (Cadieux et al., 2013). Future research could also benefit from the analysis of the needs of people with dementia in dementia-specific units and facilities, as well as examination of differences in needs between genders, ethnic groups and various medical conditions (Cadieux et al., 2013).

Furthermore, from a sustainability perspective, more research should utilize longitudinal research design to measure the impact of PCC on the organization, staff retention and resident satisfaction. Also, future research should pay attention to reliable methodological standards to strengthen the evidence; larger sample size, objective and subjective data collection, research with control and comparison groups, pre-test and post-test evaluation would be dependable factors. Established standard definitions and descriptive terms from the onset would also reduce ambiguity and assumptions in prospective research.

Future studies that focus on theory-driven interventions in care practices and organizational structures could reinforce buy-in and motivate all stakeholders i.e. residents, staff, administrators and leaders to promote person-centered care. This exercise would be crucial to dissect the organizational barriers and identify solutions to these obstacles prior to executing a person-centered care approach within long term care.

5.3 Conclusion

Long-term care facilities have typically been places of care for its residents guided by the principles of the medical model of care. The aging population, especially the baby boomers advocate for reforms in the long term care industry to provide exemplary quality of care delegating control and decision making to the residents (Brownie & Nancarrow, 2013). Person-centered care responds to these contemporary demands of LTC clients by promoting organizational culture and care practices that value the residents rather than objectify them. Although person-centered care was first introduced to protect the personhood and strengths of people with dementia, this review assesses the applicability of this care approach to all care facilities with residents in need of significant care. Person-centered care has the potential to be effective in all streams of long-term care- not just for the care recipients, but also for the well-being of the care staff.

Implementing person-centered care in its truest form requires a culture change in the philosophy and values of the organizations. The organization culture needs to shift care practices from a task-oriented to a person-centered approach, promoting individualized care and decision making amongst its residents. Long-term care facilities also must evolve from a traditional bureaucratic model to flexible and empathetic care that is cognizant of the needs and demands of its residents. Often organizations that value the person-centered care model are constrained by a medical model of care that measures success objectively through tasks

completed rather than by the subjective well-being of the residents (Rockwell, 2012). Therefore, it is critical for organizations to embrace PCC into their philosophy, objectives and training at all levels of management. An important feature of person-centered care lies in the management's treatment and appreciation for its care workers to mirror the same standards as the type of care expected from them.

This review provides adequate evidence on effective care practices, organizational facilitators and barriers for PCC implementation in LTC. Long-term care facilities that aim to meet standards of excellence in care delivery while preserving the personhood of the residents should consider theory-driven interventions as well as employ the results of this study in care practice. This literature review can also assist healthcare providers, administrators, researchers, policy-makers and PCC advocates to make sensitive decisions to improve the quality of care for older adults with complex needs. In the interim, it is crucial to divert immediate attention to find realistic solutions to overcome the organizational barriers hindering the implementation of person-centered care in long term care facilities.

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Appendix A.

Summary of Articles

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Abma & Baur (2015)	User involvement in long-term care. Towards a relational care-ethics approach	To assess the practical approach to relational care between residents and professionals in long term care to increase resident involvement	Action research project	7 female residents and several staff	Care-ethics approach to user involvement strengthens partnership between clients and staff and increases resident empowerment.		RCC
Alharbi, Ekman, Olsson, Dudas & Carlstrom (2011)	Organizational culture and the implementation of person centered care: Results from a change process in Swedish hospital care	To assess the impact of organizational culture on patient certainty, mostly to identify its impact on patient healthcare outcomes	Quantitative	5 hospital wards of one clinic	Change can occur when the organization culture values stability, flexibility, and trust.		PCC
Barbosa, Sousa, Nolan & Figueredo (2014)	Effects of Person-Centered Care Approaches to Dementia Care on Staff: A systematic review	To evaluate the impact of person-centered care practices on staff stress, burnout and job satisfaction caring for people with dementia in long term care facilities	Review		The differences in data collection and analysis limit conclusive results on job stress, burnout and satisfaction.	Methodological differences in the studies questions the effectiveness of the collected data.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Berkhout, Boumans, Mur & Nijhuis(2009)	Conditions for successfully implementing resident-oriented care in nursing homes	To assess the factors necessary for a successful implementation of a resident-oriented care model	Mixed methods quantitative and qualitative		The 7-s model by McKinsey combine the individual and organizational requirements to bring organizational change. Nursing staff play major role in redesigning work and organization. Successful implementation of PCC does not solely depend on financial and personnel means.		PCC
Bowers & Nolet (2011)	Empowering direct care workers: lessons learnt from the Green House Model	To examine the effects of empowering direct care workers in the the Green house model	Qualitative-grounded dimensional analysis	68 direct care workers, 28 licensed nurses, 8 management	The meaning of empowerment by direct workers translated as not being told what to do. Conflict resolution becomes a challenge for direct care workers in teams.	Small sample-single site. Not longitudinal therefore not possible to see overtime effects of empowerment. Observers not immersed into the setting and relied on staff for reports causing bias and possible elimination of information.	PCC/ RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Brooker (2004)	What is person-centered care in Dementia?	To review the elements necessary in providing person-centered care to people with dementia	Literature Review		Identified four necessary elements i.e. VIPS when providing dementia care to ensure optimal well-being and improved quality of care		PCC
Brownie & Nancarrow (2012)	Effects of person-centered care on residents and staff in aged-care facilities: a systematic review	To analyze the impact of person-centered care on older adult residents and care staff	Literature Review		PCC implementation is complex and requires contribution from management and care staff for success. The complexity of intervention makes it difficult to measure outcomes of approach.		PCC
Burack, Reinhardt & Weiner (2012)	Person-centered care and elder choice: A look at implementation and sustainability	To examine the implementation of person-centered care and its impact on older adults' perception of choice in daily activities in LTC	Longitudinal study	13 LTCs (Base year=69 participants; 2 yr follow-up=79 participants, 5 yr followup=68)	PCC sustainability identified as a challenge in implementation. Interventions of PCC that incorporate a more holistic approach to philosophy, staff training and organization of care may have better results.	Randomization of study conditions is questionable. Small sample size limits generalization of outcomes.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Buron (2008)	Levels of personhood: a model for dementia care	Three levels of personhood are identified and discussed along with approaches to person-centered care	Literature Review		Dementia care acknowledges the need to include the biological, individual and sociological personhood of individuals.		PCC
Cadiux, Garcia & Patrick (2013)	Needs of People with Dementia in Long-term care: A systematic review	To evaluate evidence-based care needs of people with dementia living in LTC	Literature Review		Psychosocial needs such as communication and social engagement are necessary to be included in care practices		PCC
Casper, O'Rourke and Gutman (2009)	The differential influence of culture change models on long-term care staff empowerment and provision of individualized care	To understand of the differences between Culture change models (CCM) and its effect on staff empowerment and provision of individualized care	Quantitative	Participants recruited from 54 LTCs- 177 RNs, 65 LPNs and 326 Care aides	Implementing a custom designed CCM with the inclusion of managers and staff is more durable than implementing pre-defined models such as the Eden alternative. Facility specific social models of care (FSSMOC) yield greater staff empowerment and individualized care.	Cross-sectional nature of data collection was a limitation. Longitudinal studies would provide more validated results.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Chaudhary & Cooke (2014)	Design matters in dementia care: the role of the physical environment in dementia care settings	To understand the role of the physical built environment through conceptual issues and empirical studies in enhancing the quality of life of people with dementia	Review		Specific strategies to build and modify the physical environment can be useful to improve the behavioral challenges in people with dementia		
Crespo, Hornillos, de Quiros (2013)	Factors associated with quality of life in dementia patients in long-term care	To understand the factors associated with quality of life for people with dementia (self-rated and by family and staff) living in LTC	Quantitative	102 residents, 184 relatives and 197 staff	Depression and cognitive function were best self-rated QOL. Family-rated QOL was resident functional capacity, use of feeding tubes as part of care and nursing home fees. Staff-related QOL was resident functionality, cognitive impairment and depression, staff work schedules and type of administration.	Large proportion of variance unaccounted. Mostly female sample bias.	

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Chang, Li & Porock (2013)	The effect on nursing home resident outcomes of creating a household within a traditional structure	To analyze the effect of household size in nursing homes and its impact on the behavioral, physical and psychological results of residents	Longitudinal study	2 large nursing homes	Positive effect of small scale houses on residents in the first year- better physical functioning, less sleepiness, less use of restraint. Higher rate of falls possibly due to more independence and walkability from rooms to central dining area.	Lack of control of data collection due to the use of existing MDS data collection. MDS scale may have low 'psychometric properties' which questions the reliability of current data.	PCC
Chenoweth, King, Jeon, Brodaty, Stein-Parbury, Norman, Haas & Luscombe (2009)	Caring for Aged Dementia Care Residents Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomized trial	To compare the effects of person-centred care and dementia-care mapping and routine care. Also, to test if these interventions improved quality of life and reduce aggressive behaviors.	Randomized controlled trial	15 care sites with 289 residents.	Fewer falls with dementia care mapping compared to usual care, however increased falls with person-centered care. Decreased agitation using PCC and dementia care mapping compared to usual care	Single Recorder bias	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Corazzini & Anderson (2014)	Adaptive leadership and Person-centered care: A New Approach to Solving Problems	To analyze the adaptive leadership framework and how this approach can promote person-centered care in nursing homes	Review		"Adaptive challenges" occur in complex care situations where there is not one particular solution or a technical response in nursing homes. Rethinking the solution to adaptive problems in a non-technical way through the support of front line staff may enable efficient person-centered care.		PCC
Crandall, White, Schuldheis & Talerico (2007)	Initiating person-centered care practices in long-term care facilities	To discuss the initiatives of introducing person-centered care practices in long-term care	Literature Review		Adequate coaching and training needed to initiate new person-centered care practices. Mostly facilities make incremental changes to adopt PCC.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Downs (2013)	Putting people- and compassion-first. The United Kingdom's Approach to Person-Centered Care for Individuals with Dementia	To assess the influence of person-centered care on policy making and standards of care delivery in the UK	Literature Review		Despite certain challenges, the author states that policies and standards are aptly placed to provide person-centered care for people with dementia in the UK with provision for improvements in the future.		PCC
Drick (2014)	At last: Moving into Person-Centered Care	Discusses the similarities and differences between patient centred care and person-centered care.	Literature Review		Holistic care means caring for the entire person considering their internal and external environment and needs.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Edvardsson, Sandman and Borell (2014)	Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience	To investigate the effects of PCC intervention on care and the environment, its effect on staff strain and stress of conscience	Quantitative-quasi experiment	One group pre-test/post-test design	Less staff reported stress of conscience post the implementation of national guidelines. Facility was more person-centered post intervention, more hospitable and homelike. Positive effect on staff through PC: allowed staff to provide the care they wanted to for the residents.	One group sample may have caused bias in results. Non-random sampling questions the validity of the results. All data were self-reported by direct care staff. The impact of PCC on residents and family members was not collected.	PCC
Edvardsson, Fetherstonhaugh, McAuliffe, Nay & Chenco (2011)	Job Satisfaction amongst aged care staff: exploring the influence of person-centered care provision	To evaluate the relationship between person-centered approach and job satisfaction in care staff at a nursing home	Quantitative study	297 care staff at a LTC facility	PCC can enhance job satisfaction and staff retention. Needs to shift from a task-oriented to a person-centered care approach however findings do not confirm if PCC increases job satisfaction or vice versa.	Convenient sampling limits generalizability, despite using the findings for theoretical generalization. Findings need to be validated in replicable studies for reliability. The regression model needs to be confirmed by similar studies using different samples.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Entwistle & Watt (2013)	Treating Patients as persons: A Capabilities Approach to delivery of Person-centered care	Using the Capabilities approach model in the execution of person-centered care in the healthcare system	Review		Findings suggest a model that recognizes individual capabilities to guide the type of care provided		PCC
Giebel, Challis & Montaldi (2015)	Understanding the cognitive underpinnings of functional impairments in early dementia: a review	To review the changes in the cognitive impairment of long-term memory in early dementia	Review		People with early dementia struggle with complex instrumental activities of daily living, financial tasks. Long-term memory declines the earliest.	Limited research done on the effects of everyday activities in early dementia.	PCC
Grabowski, O'Malley, Afendulis, Caudry, Elliot & Zimmerman (2014)	Culture change and nursing home quality of care	To analyze the impact of culture change on the quality of care provided	Quantitative		Culture change may improve the quality of care in nursing homes	Sample bias- "culture change" definition is based on expert panel which may not be generalizable.	PCC
Kane and Kane (2001)	What Older people want form Long-term care, And How They Can Get It	To understand the needs and preferences of older adults living in LTC and how those consumer needs can be met	Literature Review		Older adults value competent care, privacy and control in daily decision making, kindness, compassion and respect.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Kelly (2007)	Barriers to Achieving Patient-Centered care in Ireland	To discuss patient care in complex care settings in Ireland	Review		"System focused care" - nursing psyche restricts therapeutic care (often regarded as "invisible" immeasurable work which might be discouraged by managers or team leads). Routine, task oriented care may take precedence over relational care		RCC
Kelly (2014)	Bodywork in dementia care: recognizing the commonalities of selfhood to facilitate respectful care in institutional settings	To explore the practice of bodywork in care practices for people with dementia	Review		Sabat's Self 1-3 are noted to acknowledge selfhood when doing body work for people with dementia. The author urges care workers to recognize selfhood to provide empathetic care that is respectful and dignified for the recipient.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Kolanowski, Haitsma, Penrod & Yevchak (2015)	"Wish we would have known that!" Communication Breakdown Impedes Person-Centered Care	To examine how nursing staff implement PCC for people with behavioral and psychological symptoms and also the process of knowledge transfer to provide optimum care	Qualitative-Focus groups	59 staff from two nursing homes	Risk of safety for staff and residents due to BPSD, especially during the night shift when resident to staff ratio is small. Staff voiced importance of family involvement, histories and preferences of clients. Barriers to PCC- inadequate staffing, limited time, documentation		PCC
Kontos & Naglie (2007)	Bridging theory and practice-Imagination, the body, and the person-centered dementia care	To explore the importance of non-verbal communication and capacity of bodily movements to connect to a person with dementia, facilitating person-centered care	Qualitative	6 focus groups conducted with different academic healthcare facilities	Recognizing bodily experiences of persons with dementia through imagination and personal experiences, helps in providing sympathetic care. Understanding nonverbal language decreases the extra time spent in clinical practice and reduces the need for alternative drug therapy to combat restraint.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Lesta & Pecotz (2006)	Familiar group singing: addressing mood and social behavior of residents with dementia displaying sundowning	To examine the effects of familiar group singing intervention during sundowning, for residents with dementia	Qualitative - observations	4 female residents with dementia	The four day study found significant decrease in non-social behavior and improved mood and social behaviours during music sessions amongst residents experiencing sundowning in LTC	Small sample size and varied backgrounds of participants, limited time frame for data collection, untested mood-behavioral tools, bias issues (lack of internal reliability).	
Maslow, Fazio, Ortigara, Kuhn & Zeisel (2013)	From Concept to Practice: Training in Person-Centered care for people with Dementia	To identify and review concepts essential in training staff to provide person-centered care for people with dementia	Literature review		To respect the values, traditions and goals of people with dementia, despite cognitive or verbal decline and develop care plans to acknowledge the person's needs before the needs of the organization.		PCC
Mast (2013)	Bringing Person-centered care to people with early stage Alzheimer's	To review the needs of people diagnosed with early-stage Alzheimer's and the type of care to be provided	Review		Individualized plans, family involvement, moving beyond a bio-medical form of care, implementing feasible care plans are all possible measures to provide person-centered care.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
McCormack (2004)	Person-Centredness in gerontological nursing: an overview of the literature	To understand the meaning of person-centered care and practice in gerontological nursing and discuss critical models of PCC	Literature review		Being in relation, being social, being with self, being in place all important aspects of person-centredness. Relational care as critical as PCC.		PCC/ RCC
McGilton, Sidani, Boscar, Guruge & Brown (2011)	The relationship between care providers' relational behaviors and residents mood and behavior in long-term care settings	To evaluate the relationship between caregivers relational behaviors and its effect on residents' moods in different settings.	Repeated-measures design	38 residents and 35 care providers in three nursing homes	Altering care as per the needs of residents is an effective way to reduce aggressive behaviors, as all behaviors have meanings. Recognizing indicators that promote relational behaviors amongst staff would help performances.	Observer bias possible through data collection. Small sample size. Limited authenticity of results as some residents did not complete the study.	RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Molony & Bouma (2013)	The Care Manager Role in Person-Centered Care for People with Dementia	To discuss the skillful implementation of PCC for people with dementia that provides individual choices and safety.	Review		Creativity, patience and persistence allow care managers to be influential and sensitive to the voices of clients with dementia. All carers for people with dementia should educate themselves on dementia-related conditions and how to address unmet needs of those seeking help.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Mueller, Burger, Radar & Carter (2013)	Nurse competencies for person-directed care in nursing homes	To understand the competencies required by nursing staff to successfully execute person-centered care in long term care facilities	Quantitative	88 nurses	Ten traits were identified for nurses to successfully facilitate person-centered care: practice effective communication skills, include person directed care in daily routine, be a team player, identify barriers to person centered care and how to improve it, create a system to maintain consistency in care practices, be a good role model for person centered care, include team members and families in the overall care of residents		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Nolan, Davies, Brown, Keady & Nolan (2003)	Beyond 'person-centred' care: a new vision for gerontological nursing	To critically evaluate person-centred care approaches and offer an alternative relationship based care approach for the care of the vulnerable aged population	Review		The SENSES framework considers the subjective and perceptive approach to interpersonal care, with the belief that caregiving should be a beneficial experience for all involved. 2. Relationship centered care opposes the idea of autonomy and independence as means of being person-centered. It promotes care that is interdependent and provides a sense of belonging to the care giver and recipient		RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Norton (2010)	Sustaining a person-centered care environment	To evaluate the implementation of PCC in continuing care retirement communities	Quantitative	Questionnaires distributed to 524 residents and 392 staff in 6 communities	Barriers to PCC implementation were financial and structural limitations, lack of training and communication within staff and resistance to change, which could be overcome by education, innovation and learning from best practices within the community.		PCC
Nowell, Thornton & Simpson (2011)	The subjective experience of personhood in dementia care settings	To examine the subjective experiences of those with dementia	Qualitative		Three themes were identified as subjective experiences: to work the system and adapt to it, to use the past and future experiences for the present times and to manage the dual roles of being an individual and member of the group.		

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O'Connor, Phinney, Smith, Small, Purves, Perry, Drance, Donnelly, Chaudhary & Beattie (2007)	Personhood in dementia care: Developing a research agenda for broadening the vision	To devise a framework that is guided by review and synthesis of the literature to organize future research in this field to examine the meaning of personhood in dementia care	Research agenda		Three interrelated domains of inquire should be considered: the subjective experience of people with dementia, the interactional environment and the wider socio-cultural contact.		
O'Dwyer (2013)	Official conceptualizations of person-centered care: Which person counts?	To examine the official standards of person-centered resident care in long term care in Ireland	Case study		Irish model limits its understanding of the "psycho-social needs" or individual needs of the residents. It rather focuses on "autonomy" and "choice" conforming to a consumer-driven/hotel like standard of care.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Passalacqua & Harwood (2012)	VIPS Communication Skills Training for paraprofessional dementia caregivers: An Intervention to Increase Person-Centered Dementia Care	To assess the feasibility of the VIPS model to increase person-centered care communication in paraprofessional dementia caregivers in LTC	Quantitative	26 care staff at special dementia care homes	VIPS training reduced depersonalized care and increased empathetic care. VIPS suggested as a tool to improve quality of care for people with dementia	Small sample size. Ethical issues were a concern for implementing untested intervention on large group sizes.	PCC
Qidwai, Ashfaq, Khoja & Rawaf (2012)	Access to person-centered care: A perspective on status, barriers, opportunities and challenges from the Eastern Mediterranean Region	To analyze the social, cultural, religious and economical barriers to providing person-centered care in the Eastern Mediterranean region	Literature review		Poor support from private sector, lower financial resources, poor patient care attitudes of care providers, for-profit mentality and limited awareness limits quality access to healthcare.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Ripich, Wykle & Niles (1995)	Alzheimer's disease caregivers: the focused program. A communication skills training program helps nursing assistants to give better care to patients with disease	To evaluate a communication skills program for nursing assistants that care for patients with Alzheimer's Disease	Quantitative	17 nursing assistants	FOCUSED curriculum improved care staff's attitude towards people with Alzheimer's and increased their knowledge and communication skills of strategies and techniques to communicate effectively with patients.		PCC/RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Robinson & Rosher (2006)	Tangling with the barriers to culture change	To analyze the successes, challenges, barriers and impact of implementing culture change on management, direct care staff and faculty researcher in a nursing home	Quantitative	151-bed nursing home	After a 2 year implementation phase of Eden Alternative at the facility, family satisfaction increased, depression amongst cognitively intact and impaired residents decreased, and staff indicated higher purpose and meaning to their job. However, staff did not feel more involved in decision-making within the organization.		PCC
Rockwell (2012)	From Person-centered care to relational care: expanding the focus in Residential care facilities	To investigate the structural barriers of PCC in LTC and understand the importance of meaningful relationships of resident and staff	Qualitative	4 social workers and 1 physician	Organizational barriers reduced by using relational care. More attention should be devoted to resident, staff and family relationships	Small sample size limits generalization of the findings.	RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Rosemond, Hanson, Ennett, Schenck & Weiner (2011)	Implementing person-centered care in nursing homes	To utilize the innovation implementation theory to implement person-centered care in nursing homes	Multiple case study		Three useful factors in implementing person-centered in nursing homes: scope of the project, communication with management and implementation climate.		PCC
Sabat (2002)	Surviving manifestations of selfhood in Alzheimer's disease	To explore the aspects of selfhood through the social construction theory lens	Case Study	One individual with Alzheimer's disease	Findings indicate selfhood is not lost in moderate to severe stages of Alzheimer's Disease. Potential losses are constructed through the lens of health providers that see the person with Alzheimer's as burdensome and weak. Mitigating these biases can result in dignity and enhanced communication for the person with AD while coping with the disease.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
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Sabat & Lee (2011)	Relatedness among people diagnosed with dementia: Social cognition and the possibility of friendship	To explore the social cognition in people with moderate dementia in adult day centers	Qualitative	Observations made over 4 months	Verbal and non-verbal communication was found to facilitate meaningful communication amongst participants and care workers.		PCC
Sampsel (2003)	The promise, practice and problems of the Eden Alternative	To review the success, failures and challenges of implementing the Eden Alternative in LTC	Literature review	Eden implementation at a 450-bed LTC	Successes-increased self-care among the residents, participation in activities with animals and children, increased family visits, delegating some decision making to front line staff. Challenges- lack of training and education to frontline staff due to facility size and limited time, resident resistance to animals in the facility, lack of encouragement for community involvement of residents.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Sarkoma, Tervaniemi, LicPhil, Numminen, Johnson, & Rantanen (2013)	Cognitive, Emotional , and Social Benefits of regular musical activities in early dementia: Randomized Controlled Study	To assess the efficacy of music intervention based on caregiver training for people with dementia	Qualitative	89 people with dementia and caregiver dyads	Regular singing enhanced the short and working memory of people with dementia and music had a positive effect on quality of life of residents	Study was not focused on particular types of dementia limiting the conclusion general effectiveness. People with early dementia were not included I the study. Due to funding and scheduling limitations, the study period was short.	PCC
Savundranayagam (2014)	Missed Opportunities for person-centered communication: implications for staff-resident interactions in long-term care	To observe if routine staff- resident interactions were person-centered manner and to investigate missed opportunities for person-centered care	Quantitative research	Conversations recorded (N=46) between staff and residents with moderate to severe AD	PCC communication can occur in four ways: recognition, validation, negotiation and facilitation. Missed opportunities for PCC happen when these four categories are neglected when communicating with residents.	Small study size. Study only focused on one type of staff and activity.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Stein-Padbury, Chenoweth, Jeon, Brodaty, Haas & Norman (2012)	Implementing Person-Centered Care in Residential Dementia Care	To discuss the training and procedures employed to implement PCC, after proving PCC to be effective in reducing agitation amongst people with dementia.	Randomized Controlled Trial	RCT in 15 residential care facilities with 236 residents	PCC training helps recognize non-verbal communication of residents as cues to unmet needs. PCC implementation barriers include strict demands of time and completion of multiple tasks.		PCC
Sterns, Miller & Allen (2010)	The complexity of implementing culture change practices in nursing homes	To assess the different approaches to culture change implementation and duration in nursing homes (self reported by nursing homes)	Systematic review		Incremental changes for culture change are more accepting and easier to adapt for staff and residents. Simpler PCC practices with minimum staff input or help was easy to implement.		PCC
Stevens-Roseman & Leung (2004)	Enhancing Attitudes, Knowledge, and Skills of Para professional service providers in Elder Care Settings	To examine the impact of gerontological training on the knowledge and skills of paraprofessionals and resident satisfaction	Quantitative	74 para professional s (72% females)	Specific training on aging related issues develop skills and attitudes, as well as aide in improving client satisfaction. These changes are progressive and may require ongoing support.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Talerico (2004)	The family's role in person-centered care	To assess the role of family in providing person centered care in long term facilities	Reviews		The family plays a role in providing information for the staff to learn more about the residents, connecting residents to the community, and ensuring their family members receive the care and love they need.		PCC
Taylor & Taylor (2013)	Person-Centred Planning: Evidence-Based Practice, challenges and potential for the 21st century	An overview of person-centered planning to improve the lives of those with intellectual disabilities and provide support to their caregivers.	Literature Review		Planning for PCC takes precedence over implementation. Benefits of PCP: increased respect, more participation, independence and increase in staff interest. Important to implement values of PCP even if it does not bring the desired outcome.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
te Boerhorst, Willimse, Depla, Eefsting & Margriet (2008)	Working in group living homes for older people with dementia: the effects on job satisfaction and burnout and the role of job characteristics	To analyze the job satisfaction of nursing staff in small group homes versus traditional nursing homes	Quantitative	183 caregivers in group living homes and 197 caregivers in traditional nursing homes	Job satisfaction and well-being was higher for care staff in small group homes with lower demands and increased social support from colleagues	The differences in the resident population or the participants in the study limit the assessment of direct impact on job burnout and satisfaction. Also, psychological characteristics of staff were not taken into account, which could have been confounded in the results.	PCC
Tellis-Nayak (2007)	A Person-Centered Workplace: The Foundation for person-centered caregiving in Long-Term Care	To examine the role of managers in transitioning from a traditional to a person-centered long term care facility	Quantitative	2 surveys conducted in 156 nursing facilities	Managers play an important role in staff job satisfaction, loyalty and commitment. Staff engagement and satisfaction occurs when managers practice non-medical and person centered approach to care.	Sample's representation of the general population is questionable. Data collected was not implicit to the research questions of this study doubting its reliability.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
viau-Guay, Bellamere, Feillou, Trudel, Desrosiers & robitaille (2012)	Person-Centered Care Training in Long-Term Care settings: Usefulness and facility of transfer into Practice	To assess the usefulness and implementation of relationship-based care training given to caregivers in long-term care facilities	Quantitative	Open ended questionnaires circulated to 392 trained caregivers	Barriers of relationship centered care at the facility: lack of training, personal factors such as reluctance to change or belief in the medical model of care and, resident and family characteristics. Only training is insufficient to transform care practices, individual beliefs should also be considered.		RCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Vikstrom, Sandman, Stenwall, Bostrom, Saarnio, Kindblom, Wdvardsson & Borell (2014)	A model for implementing guidelines for person-centered care in a nursing home setting	To analyze a model to implement evidence-based guidelines to implement person centered care for people with dementia in long term care homes. Also to analyze the staff experiences upon implementation	Participatory research		Implementation and integration of new practices is challenging and takes practice. Using action-approached and educational seminars like small group interaction, knowledge transfer, team workshops poster exhibits would be productive. Lack of time perceived as a potential barrier to bring about change and implementation.		PCC
Vink, Zuidersma, Boersma, Jonge, Zuidema & Slaets (2013)	The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: a randomized controlled trial	To compare the influence of music therapy and other recreational activities in reducing agitation for people with dementia in LTC	RCT	94 residents with dementia	Music therapy and recreational activities yielded a short-term reduction in agitation amongst people with dementia, with no additional long-term care benefits	A modified version of CMAI was used to assess agitation behaviors, which lacks the scale provided in the full version. Possible bias in rating scores due to conflicting jobs of the nurses. Being unaware of the exact purpose of the study may have resulted in positive bias towards results.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Willimse, Downs, Arnold, Smit, de Lange & Pot (2015)	Staff-resident interactions in long-term care for people with dementia: the role of meeting psychological needs in achieving residents' well-being	To investigate the role of staff-resident interactions in meeting the psychological needs of residents and aiding in their well-being	Qualitative - observations	51 residents in 9 LTCs	"Personal enhancers" are social interactions that meet the needs of people with dementia while "personal detractors" undermine their needs. Findings confirm the social constructionist and humanist theories of dementia by Kitwood & Bredin and Sabat & Harre.	Small sample size. Observed care practices in limited no. of LTCs. Findings from this study do not conclude a definitive result of well-being triggers.	PCC
Williams, Harris, Lueger, Ward, Wassmer & Weber (2011)	Visual Cues for Person-centered Communication	To assess the effect of automated digital displays (photographs) of residents to remind staff of personhood and increase communication	Qualitative	6 residents and ten nursing staff	Person-centered staff-resident interactions initially occurred as a result of the digital photo frames. However, the 3-month follow up reported no increase in communication or near baseline interaction possibly because the photos did not serve opportunity for new dialogue or repeated viewing reduced its importance.	Staff and resident verbal communication may have been filtered because conscious of being recorded. Small sample size was not randomly selected. Selection bias. Other unaccounted variables could have prompted a change in communication.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
White-Chu, Graves, Godfrey, Bonner & Sloane (2009)	Beyond the Medical Model: The Culture Change Revolution in Long-Term Care	To highlight the key elements of culture change through staff-resident relationships, workforce design, leadership abilities and eliminating medical jargon. Case study presents implementation process of PCC in LTC.	Review		Culture change outcome has mixed reviews. Leadership is central in culture change.		PCC
Zeisel (2013)	Improving Person-centered care through effective design	To review design guidelines that provide opportunity to maintain personhood and build strong relationships for people with dementia in care facilities.	Literature Review		Environmental cues remind people with dementia of who they are and signal them appropriate behavior. A homelike, noninstitutional environment preserves the personhood and maintains routine for residents with dementia.		PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Zeisel, Silverstein, Hyde, Levkoff, Lawton & Holmes (2003)	Environmental correlates to behavioral health outcomes in Alzheimer's Special Care units	To measure the relations between seven environmental design features and incidence of depression, agitation, social withdrawal and psychotic issues amongst people with dementia living in special care units	Quantitative	427 residents in 15 special care units	Selective design features empower resident autonomy, reduce incidence of depression and social withdrawal.	Unspecified factors excluded from the study. Random distribution was assumed; individual behavioral health characteristics may have affected the measures. Limited number of sites participated.	
Zhong & Lou (2013)	Person-Centered Care in Chinese residential care facilities: a preliminary measure	To validate a PCC measuring tool suitable in the Chinese context-identified as a barrier in implementing PCC in dementia care residential facilities in China	Quantitative	458 questionnaires (success rate of 75.3%) redistributed to 34 residential facilities in 6 urban areas of Xi'an	The P-Cat measurement tool was successful in measuring PCC in the Chinese context after revisions to meet the cultural and organizational differences of the country. PCC can be achieved through a partnership between formal and informal caregivers and staff coherence.	The P-CAT scores were comparatively low. The study was only conducted in one rural city.	PCC

Reference	Title	Focus of Study	Method		Key Findings	Limitations	PCC/ RCC
			Research Design	Sample Info			
Zimmerman, Shier and Saliba (2014)	Transforming nursing home culture: Evidence for Practice and Policy	An overview of the history of culture change, its challenges and discussion on some culture change models	Review		Complex needs of residents prioritize quality of care over quality of life. The term "culture change" may be more of a hindrance in developing good standards to care		