

IS LONG-TERM CARE PERSON-CENTRED? A CASE STUDY

by

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Abstract

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In Ontario long-term care (LTC) settings, person-centred care (PCC) is promoted by government legislation, accreditation organizations and professional practice guidelines aiming to integrate this approach. However, there is currently no standardized approach to providing PCC in LTC. The purpose of this study was to examine public policies on PCC in Ontario and explore how they are interpreted and translated into practice in LTC. A qualitative case study approach was used to examine the perspectives of key stakeholders at one LTC facility in Ontario. Focus groups were conducted with residents, family members, direct care providers and managers. Through content analysis, findings were organized into four categories showcasing both overlapping and differential understandings of PCC in practice: 1) conceptualization, 2) barriers, 3) facilitators, and 4) evaluation. Identified tensions between policy and the delivery of PCC highlight systemic issues that must be addressed to enable equitable person-centred LTC rooted in resident-identified priorities.

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I would lastly like to thank everyone who expressed an interest in learning about my thesis, reading the final product or acknowledging the importance of the subject. I believe it is possible to deliver long-term care that meets the needs and preferences of residents. I believe it starts with greater awareness and recognition of the value in every person, especially those who are aging near the end of their lives and those living with the effects of debilitating illness.

Dedication

This thesis is dedicated to my good friend, Harold Taube – an artist, humorist and resident of long-term care.

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1.0 Introduction

In Canada, all provinces have regionalized health services in an effort to provide improved access and coordination across the continuum of care including hospitals (acute care), long-term care (LTC), home and community care as well as mental health and addiction services (Bhasin & Williams, 2007; Ontario Health Coalition, 2001). The additional impetus for regionalization was to bring the organization of care closer to recipients' homes and communities while engaging citizens in the process (Bhasin & Williams, 2017; Chessie, 2009). Engagement is one tool of a patient-centred approach, which in healthcare settings, recognizes and integrates a value for the patient voice (Fooks, Obarski, Hale & Hylmar, 2015). In 2001, the Institute of Medicine (IOM) included patient-centred care in their recommendations for reorienting the delivery of healthcare in the United States (IOM, 2001). Patient-centredness was conceptualized by the IOM (2001) as “providing care that is respectful of and responsive to individual patient preferences, needs, and values” (p. 3). The IOM provided a benchmark that prompted global efforts to integrate a patient-centred approach in healthcare across jurisdictions.

In Ontario, the formal commitment to a patient-centred approach can be traced back to 2010 with the passing of the Excellent Care for All Act (ECFAA). The ECFAA endorses patient-centredness as part of a high quality healthcare system, and includes regulations for quality monitoring to promote the patient experience as a priority for healthcare organizations (Legislative Assembly of Ontario, 2010). Subsequent amendments to the ECFAA included provisions to ensure that Health Quality Ontario (HQO) had a stronger role in the promotion and monitoring of patient engagement, as this became a mandatory indicator in hospital quality improvement plans (Legislative Assembly of Ontario, 2014). The subsequent Patient's First Act (PFA), in 2016, further pushed for patients' needs as preeminent, as the goals of this legislation

included improving access to coordinated care and cultivating opportunity for greater patient involvement (Legislative Assembly of Ontario, 2016). In addition, funding opportunities in health research have become frequently linked to evidence of patient-centredness. For example, the Canadian Institutes for Health Research has a specific funding stream, the Strategy for Patient-Oriented Research, to ensure research includes both patient partnerships and engagement efforts (Canadian Institutes for Health Research, 2018). The pervasive popularity of patient-centredness places it in the spotlight of Ontario's healthcare system today.

In line with the drive for patient-centred care, Ontario began promoting the delivery of health services through the home and community care sector. In 2007, the Aging at Home Strategy reflected Ontario's shift to supporting people to stay in their homes across the life course as a priority over moving into long-term care (Ontario Legislative Library, 2007). In addition to the fact that the majority of Ontarians report home as their preferred setting of care, homecare is cost efficient for the healthcare system (Canadian Healthcare Association, 2009; Canada Mortgage and Housing Corporation, 2012; Canadian Institute for Health Information, 2011). A focus on home and community care was additionally driven by the undeniable evidence that the majority of older adults will require assistance in at least one aspect of their daily lives as they age, which is especially pertinent in the face of an aging population (Canada Mortgage and Housing Corporation, 2012; Canadian Institute for Health Information, 2011). By 2052, those aged 85 years and older will make up the largest proportion of the aging population, with 25% of this age demographic typically reporting moderate, severe or total impairment in their capacity to carry out tasks of everyday life (Canadian Institute for Health Information, 2011). The rising demand for care is additionally reflective of a higher life expectancy among the elderly and the

common development of multiple chronic conditions (Canadian Institute for Health Information, 2011).

However, in Ontario, the supply of publicly funded home and community care is not meeting the growing demand for care in this sector, resulting in a substantial portion of financial costs being shouldered by clients and their families, which is not sustainable for the average citizen (Ontario Health Coalition, 2001). An alternative to receiving support at home is being institutionalized in a LTC setting where publicly funded care is provided 24 hours a day for individuals with physical and/or cognitive impairments. In light of Ontario's efforts to promote greater uptake of home and community care services, eligibility for LTC shifted to only those with complex and high level care needs in 2010 (OLTCA, 2019). As of February 2019, there were 78,247 LTC beds across Ontario (OLTCA, 2019), highlighting the continually significant population that depends on this type of care setting.

In 2018, new political leadership was established in Ontario as Premier Doug Ford, of the Conservative party, replaced a long-standing Liberal government. As part of their ten-year plan, Premier Ford's government has pledged to deliver 30,000 additional LTC beds in response to the growing demand for care and overcrowding in hospitals (Breen, 2018). A shift in Ontario away from endorsing home and community care and towards a commitment to the expansion of the LTC sector is apparent. Under the leadership of Premier Ford, the Ontario Ministry of Health and Long-term Care (MOHLTC) has additionally continued to endorse a patient-centred approach across the healthcare system (MOHLTC, 2018). However, years of enduring concerns for the quality of LTC care and the quality of life of residents (Coughlan & Ward, 2007; Long-Term Care Task Force Ontario, 2012; Choiniere et al., 2016) suggests the need for a more in-depth examination of the congruence of LTC with a patient-centred care approach.

Evolution in Long-Term Care

Reports of abuse, neglect and unhygienic living environments in LTC are prevalent in Canadian media (Coughlan & Ward, 2007; Long-Term Care Task Force Ontario, 2012; Pederson, Mancini & Ouellet, 2018). Media outlets have highlighted stories of disgruntled family members and probed further to examine the incidence of poor quality care. A recently completed six-year investigation of LTC by the Canadian Broadcasting Corporation (CBC) revealed an increase of 148% in abuse rates since 2011 (Pederson, Mancini & Ouellet, 2018). In 2018, CBC News also launched a video series titled “Crying Out for Care” which explored stories of abuse in LTC and the lingering system level issues related to understaffing and underfunding (CBC News, 2018). In recent years, the case of Elizabeth Wettlaufer, a registered nurse who was convicted of murdering eight Ontario LTC residents, drew greater attention to staffing regulations and resident vulnerability (Grant, 2018). In addition to the media, advocacy organizations have long since acknowledged issues in LTC (AdvantAge Ontario, 2018). In response to rising rates of maltreatment uncovered by CBC News, AdvantAge Ontario noted that the recent implementation of stricter reporting requirements, as well as the ongoing challenges of an aging population, complex care needs, and limited funding may help to explain these findings (AdvantAge Ontario, 2018).

Despite widespread awareness, no action has been taken by the government to review issues related to standards of care across the province (Grant, 2018). Instead, efforts are ongoing to monitor and report the quality of care in LTC homes (Williams et al., 2015). Defining and assessing the quality of LTC is debated in the literature, with the majority of research focused on developing performance metrics (Coughlan & Ward, 2007). In line with this approach, Ontario adapted an assessment of LTC conditions through HQO. In 2015, HQO developed quality

indicators for LTC which are monitored regularly and made publicly available. These include wait-times, antipsychotic medication use, fall rates, physical restraint use, as well as incidence of pressure ulcers, pain and depression (HQO, 2015). In addition, the Ontario MOHLTC partnered with multiple organizations in the LTC sector to release a five-year strategy under HQO titled “Residents First” in 2011. Central themes in this strategy include training staff about reducing emergency department visits, improving resident experience and continence care, preventing pressure ulcers and falls, and increasing workplace efficiency (HQO, 2012). A focus on quality improvement has been echoed elsewhere, including a report by Sinha (2012) titled “Living Longer, Living Well” developed to inform policy for the Ontario government’s Senior Strategy.

The development of quality indicators has additionally increased the prevalence of accreditation services across the healthcare system, inclusive of LTC. Prominent organizations include Accreditation Canada and the Commission on Accreditation of Rehabilitation Facilities (CARF) International. LTC homes that meet the accreditation standards of these associations are awarded a premium by the MOHLTC, thus incentivizing a focus on continuous quality improvement (CARF International, 2008). While quality assurance measures have become embedded in LTC practices, some argue that they represent a reductionist approach to evaluating residents’ experiences of living in LTC and the care provided (Coughlan & Ward, 2007).

LTC has historically operated as an institutional care setting with a focus on the medicalization of residents in a hospital-like environment (Flesner, 2009). The existing methods of quality assurance reflect this approach as they largely concentrate on narrow clinical aspects of care (Coughlan & Ward, 2007; Choiniere et al., 2016). However, there has been an ongoing movement to embrace alternative models of care that extend beyond the provision of medical care (OLTCA, 2018). Innovative care models that challenge the institutional environment of

LTC and a task-focused workforce have contributed greatly to a conversation of change. A patient-centred care approach is more commonly referred to as a ‘person-centred’, ‘resident-centred’ or ‘family-centred’ approach in the LTC context. For the remainder of this thesis, the term ‘person-centred’ will be used for consistency.

In Ontario, person-centred LTC has been propelled by government legislation, organizational and professional policies as well as support from advocacy organizations (see Figure 1). Person-centredness in LTC settings is aligned with a greater focus on quality improvement and the resident experience. However, there are currently no mechanisms in place to facilitate the systematic implementation of a person-centred approach in LTC settings. The purpose of the current study was to examine person-centred care (PCC) through a qualitative case study of one LTC facility in Ontario. This study aimed to provide a contextual account of how person-centredness is conceptualized in policy and in practice. The remainder of this thesis will include a literature review on PCC and its evolution in Ontario and in LTC, followed by a description of the study methods, results, discussion, policy implications and organizational recommendations and conclusions.

Figure 1. Evolution of Long-Term Care in Ontario



2.0 Review of the Literature

Person-Centred Care

Over the last 30 years, person-centredness has been woven into a complex web of ideas, characteristics, and principles across health services. In the literature on PCC, most authors preface their discussions on the topic with a commentary on personhood (McCormack, 2004; Caspar, O'Rourke & Gutman, 2009). The historical works of Immanuel Kant, rooted in philosophy (Sullivan, 1990), and those of Carl Rogers (1961) and John Heron (1992), founded in psychology, are most commonly cited as the origins of thought that inform ideas of personhood and thus, person-centredness (McCormack, 2004; Caspar et al., 2009; McCance, McCormack, Dewing, 2011).

The translation of person-centredness into care settings is frequently credited to Tom Kitwood (1997), who explored the concept of personhood for people living with dementia. As dementia disproportionately affects older adults, Kitwood's (1997) conceptualization of personhood is further credited for focusing discussions of PCC among geriatric populations (McCormack, McCance & Dewing, 2011). Kitwood (1997) defines 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" (p. 8). While used as a common reference point for the delivery of PCC, translating personhood into standardized healthcare practice has proven to be an ongoing challenge.

Researchers investigating PCC across a variety of healthcare settings continue to frame PCC as difficult to define (Dewing & McCormack, 2017). The result is multiple terms and working definitions that exist across the literature in attempts to accomplish the complex task of translating person-centredness into a practical conceptualization. For example, in the context of

acute care, Mead & Bauer (2000) synthesized definitions across the literature to provide five key dimensions of patient-centredness: a biopsychosocial perspective, 'patient-as-person', sharing power and responsibility, therapeutic alliance, and 'doctor-as-person'. McCance, McCormack & Dewing (2011) explored the nursing literature and concluded that a notable component of person-centredness is trusting, understanding and knowledge-sharing relationships between providers, patients and families. In a literature review of PCC for older adults, Kogan (2016) identified five prevalent characteristics: coordinated care, focus on a target population, team-based, connected medical and support services, and the involvement of patient, family and friends. These findings reflect a condensed example of the efforts of researchers to aggregate the literature on PCC. Despite these efforts, PCC is continually discussed with an acknowledgement of the ambiguity surrounding it and resulting variability in approaches to conceptualize and study it (McCormack et al., 2015; Waters & Buchanan, 2017). Thus, despite a historical foundation, a standard definition of person-centredness in healthcare remains elusive across the literature.

Person-Centred Long-Term Care

In a review article by Koren (2010), innovation in LTC is discussed in the broader context of a culture change movement, born out of the United States in the 1980s (Koren, 2010). In 1986, the IOM published the first report to use the term 'residents' to describe people living in LTC and further called for the creation of a home environment in place of an isolated focus on nursing care (Koren, 2010). Continued momentum for change is credited to the work and collaboration of advocacy from residents and their families, and policy change with the goal of improving quality of care and quality of life (Koren, 2010). Culture change is noted to

encompass evolution in resident care, organizational and human resource practices, and environmental design (Koren, 2010).

The emergence of PCC in LTC is intertwined in the culture change movement, which spurred the development of numerous models of care, such as the Eden Alternative and the GentleCare approach (Caspar et al., 2009). The Eden Alternative was developed in the United States in 1991 to combat psychological suffering among LTC residents and promotes autonomous decision-making for residents and front-line staff, humanized nursing care as well as the breakdown of administrative power hierarchies (Caspar et al., 2009). Moyra Jones, a Canadian occupational and physiotherapist in gerontology, coined the GentleCare approach in 1996 (Davies, 2016; Caspar et al., 2009). GentleCare involves a focus on individualized care planning that includes residents with dementia and their families, lower resident to staff ratios, increased staff education, permanent staff assignments, and enhanced physical environments (Jones, 1999; Caspar et al., 2009). Similarly, the Pioneer Network, from the United States, is an organization of providers and LTC advocates that emerged in 1997, aiming to provide individualized care, implement a home-like environment, and enhance autonomy for front-line workers to support an evolution in LTC (Koren, 2010). Later models aimed to further reimagine LTC, such the Green House Project, established in 2003 in the United States, which seeks to provide a meaningful life for residents outside of an institutional setting in stand-alone homes and empower staff with education (Li & Porock, 2014; The Green House Project, 2019). These models translate the ideas of culture change into practice alternatives that are in contrast to the traditional biomedical model of LTC that focuses on task-based disease management rather than prioritizing the experience of residents (Entwistle & Watt, 2013).

However, despite widespread awareness of the culture change movement, researchers highlight a lack of adoption of such models (Koren, 2010). Importantly, empirical research evaluating the effectiveness of these care models supporting culture change is scarce (Caspar et al., 2009; Williams et al., 2015). In general, efforts to improve LTC have been met with varied success and are challenged by the lack of standardization in an evolved approach to care and tools to measure effectiveness (Brownie & Nancarrow, 2013; Clarke, Ellis, Thombs & Clarke, 2017; Jones, 2011; Koren, 2010). In addition, available peer-reviewed findings point to conflicting evidence on the impact on resident outcomes (Caspar et al., 2009; Brownie & Nancarrow, 2013). Research examining the Eden Alternative showed no significant effects on residents' satisfaction with care, quality of life and psychosocial well-being, as well as no changes on employee related variables such as staff satisfaction and turnover rates (Ruckdeschel & Van Haitsma, 2001; Brooke & Drew, 1999). While the Green House Project has showed a positive impact on resident-reported quality of life, researchers note findings are not generalizable to typical LTC settings which remain structured as institutions in stark contrast to the small, stand-alone homes of the Green House Project (Kane, Lum, Cutler, Degenholtz & Yu, 2007; Caspar et al., 2009). No published research has evaluated the impact of the GentleCare approach (Caspar et al., 2009).

Despite a lack of concrete, transferable evidence, these models are seen as early innovations that promoted a focus on person-centred LTC (Caspar et al., 2009; Koren, 2010; Kane, 2001). However, the challenge of determining the uptake and effectiveness of person-centred practices is compounded by the absence of public reporting from LTC homes that may have adopted various models or philosophies of care rooted in person-centredness. Therefore, a considerable gap in knowledge exists that must be filled by researchers exploring person-centred

LTC; including, what it means and how it is implemented into routine practice. The literature supports a general consensus that while movements towards culture change and person-centredness have existed for three decades, efforts and strategies to standardize implementation continue to lag behind (Kane, 2001; Williams et al., 2015).

Person-Centred Long-Term Care in Ontario

Across North America, a push for change in LTC settings is noted as a product of years of reporting on poor quality care, including incidences of abuse and neglect frequently publicized by the media, and a lack of government accountability to enforce policies to improve quality (Caspar et al., 2009; CBC News, 2018). In response, the Long-Term Care Homes Act (LTCHA) was introduced by Ontario in 2007 and later enforced in 2010. The LTCHA replaced three existing statutes: Nursing Homes Act and Regulation; Charitable Institutions Act and Regulation; and Homes for the Aged and Rest Homes Act and Regulation. The LTCHA's fundamental principle, outlined by the Legislative Assembly of Ontario (2010), states that: "a long-term care home is primarily the home of its residents and is to be operated so that it is a place where they may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met (c. 8, s. 1). The MOHLTC (2011) further outlines that the LTCHA is "designed to help ensure that residents of long-term care homes receive safe, consistent, high-quality, resident-centred care" (p. 1). The LTCHA additionally includes a preamble that refers to a belief in 'resident-centred care', however, that term is not explicitly defined, nor is it mentioned again. The 2010 enactment of the LTCHA enforced new guidelines including additions to the Residents' Bill of Rights (Appendix

A), care plans to meet individual resident needs, and preventative care programs (Legislative Assembly of Ontario, 2010).

The Advocacy Centre for the Elderly (2010) outlines the LTCHA as a “fundamental shift in the way long-term care is regulated” (p. 1) with expectations of increased transparency, consistency and compliance across the sector (Advocacy Centre for the Elderly, 2010). The MOHLTC (2011) states that the amended Residents’ Bill of Rights “expands on and strengthens” the previous set of rights (p. 9). A total of 27 rights are enforced across the categories of dignity and respect, prevention of abuse and neglect, care and services, consent and choices, minimizing of restraints, communications, concerns or complaints, and other (i.e., financial affairs) (MOHLTC, 2011).

The ECFAA (2010) came into effect just following the LTCHA with the following statement: “a high quality health care system is one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe” (p. 1). Subsequent provincial policies emerged over the years with a focus on PCC, which added to the momentum. These included; the 2012 Ontario Action Plan, the 2015 Patients’ First policy document and the 2016 PFA (Kuluski et al., 2016). Following a change in Ontario’s political leadership in 2018, Premier Ford commissioned a Council on Improving Healthcare and Ending Hallway Medicine. The most recent report, released in June 2019, titled, “A Healthy Ontario: Building a Sustainable Health Care System” continues to promote person-centredness as in line with high quality care delivery (Premier’s Council on Improving Healthcare and Ending Hallway Medicine, 2019). Together, these legislative and policy documents work to cultivate greater space for a person-centred approach in LTC.

While legislation in Ontario ignited expectations of an evolving LTC system, subsequent concrete policy guidance to standardize the conceptualization and implementation of PCC never arrived. In its place, there are discipline-specific educational materials and guidelines developed by regulated healthcare professional bodies, such as physicians and nurses, as well as unregulated care providers such as personal support workers (PSWs). In 2013, Saint Elizabeth Health collaborated with the Yee Hong Centre for Geriatric Care to develop workshops for PSWs with education and training on the concept and delivery of PCC in homecare and LTC settings. Guidelines released by the Registered Nurses' Association of Ontario (RNAO) in 2015 provided best practice recommendations for nursing care using a person and family-centred approach. Both sets of practice guidelines discuss PCC as a philosophy of care and reference various elements found across the literature related to collaborating with care recipients and their families to meet needs and promote empowered decision-making (Saint Elizabeth Health & Yee Hong Centre for Geriatric Care, 2013; RNAO, 2015).

In addition, advocacy organizations such as the Canadian Association for Retired Persons (CARP) and the Ontario Long-Term Care Association (OLTCA) use person-centred language in reference to programming, care delivery and calls for system reform (CARP, 2012; OLTCA, 2015; OLTCA, 2016). However, conceptualizing and defining person-centredness is non-existent alongside the use of the term. Thus, it may not be surprising that there is inconsistency in practices related to PCC across LTC settings, contributing to the paucity of facilities committed to implementing and evaluating a multi-dimensional person-centred approach (Brownie & Nancarrow, 2013; Jones, 2011; Koren, 2010). Slow uptake is reflected in the literature as researchers continue to debate the meaning of PCC and how it can be translated effectively into LTC settings (Moore et al., 2017). As McCance, McCormack & Dewing (2011)

highlight, an ongoing lack of consensus has led to a sense of tokenism around PCC, whereby the term is used “without any real sense of what the term actually means” (p. 3). The tokenistic use of PCC in LTC comes at the expense of residents’ experiences. Therefore, it is imperative to assess how PCC is interpreted in Ontario LTC facilities and how or if it is translated into practice.

Theoretical Perspective – Street-Level Bureaucracy

This study of PCC in LTC was examined through the lens of street-level bureaucracy, which maintains that the translation of public policies into practice is impacted by how policies are experienced and perceived by front-line workers (Lipsky, 2010). From a street-level bureaucracy perspective, the autonomy of front-line workers in policy implementation shapes the experience of the population for which a policy is intended (Lipsky, 2010). Furthermore, the autonomous decision-making of front-line workers is frequently informed by constraining conditions such as limited time and resources (Tummers & Bekkers, 2013). Through this lens, the implementation of PCC in a LTC setting, as a concept embedded in recent public policy, is therefore driven by the decision-making of staff members. In the current case study, existing legislation on PCC informs the qualitative exploration of the perspectives and experiences of staff members, as well as other key stakeholders (i.e., residents and family members). Including the perspective of residents and family members provides an in-depth understanding of how staff members’ interpretation of PCC is perceived by the populations for which it is intended. A street-level bureaucracy theoretical perspective informs a hypothesis that the existence of PCC in public policy is not sufficient for consistent and effective implementation.

3.0 Methods

Research Questions

The purpose of this study was to examine the existing public policies in place on person-centred LTC for older adults in Ontario and how these policies are interpreted by key stakeholders (i.e., administrators, direct care providers, family members and residents) and translated into practice at one LTC home in Ontario, which will be referred to by the pseudonym ‘Brookfield’. The following research questions guided this study;

- 1) What are the current public policies related to person-centred LTC that are applicable in Ontario?
- 2) How do key stakeholders at Brookfield interpret and implement these policies?
- 3) How do key stakeholders at Brookfield describe how these policies translate into delivery of PCC to LTC residents in practice?

Study Design

Case study. A qualitative case study was conducted at one LTC residence in Ontario (‘Brookfield’). An instrumental case study design was used to examine Brookfield as a typical case. Hyett, Kenny & Dickson-Swift (2014) note an instrumental case study as one that “provides insight on an issue or is used to refine theory” (p. 2) and is chosen for further understanding. It is important to outline what is common and what is particular about a case in case study research, including the historical background, physical setting as well as institutional and political contextual factors (Hyett et al., 2014; Stake, 1998). This LTC residence is a typical case in that it adequately informs an understanding of a not-for-profit LTC residence in Ontario that is governed by the LTCHA. It is additionally part of the 60% of LTC homes in Ontario that

are considered large, with more than 96 beds (OLTCA, 2019). The residence is located in an urban setting and features two affiliated alternative living arrangements; assisted living and private apartments.

At Brookfield, there are six floors, with 32 residents allocated to each floor. One floor is designated as the secure floor, where the majority of residents with a diagnosis of dementia live. However, the facility operates with an integrated model of care whereby some residents with dementia live on other floors. The property includes multiple amenities, including an outdoor patio accessible only on the third floor, and a common room space on each floor. In addition, the residence provides nursing and personal care, medical care by a visiting physician, palliative and end-of-life care, furnished rooms, housekeeping and laundry, therapeutic diets and supplements, rehabilitation and restorative therapies, and recreational programming. Care is provided by a combination of PSWs, registered practical nurses (RPNs) and registered nurses (RNs). Both the PSWs and RPNs are unionized through the Canadian Union of Public Employees (CUPE). Like the majority of LTC facilities in Ontario, Brookfield is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) International as a person-centred LTC community.

Research ethics approval was obtained for this study from the Ryerson University Research Ethics Board (REB) (protocol number: 2018-483). Brookfield does not have an institutional REB. The Chief Executive Officer (CEO) of Brookfield provided written documentation that Ryerson University REB approval was sufficient to meet the organization's ethics requirements as this was approved by the CEO and Board of Directors of the organization (Appendix B).

Qualitative approach. A qualitative approach was well-suited to the objectives of this research study, which sought to illuminate how person-centredness is understood and implemented in a LTC setting. Nyamathi & Shuler (1990) note that health researchers have long recognized the important role of qualitative methods to capture “a genuine understanding of human behaviour” (p. 1283). A qualitative approach provides a systematic inquiry into the social processes that produce individual and group level understanding, and insight into individuals’ perspectives and interaction with their environment (Nyamathi & Shuler, 1990; Rosaline, 2008). By allowing an examination of the mechanisms and variables at play in a given context, qualitative methods allow for the identification of differences across perspectives and supports clarity of concepts (Rosaline, 2008). In this case study, four focus groups were conducted separately to gather the perspectives of four participant types; residents, family members, direct care providers and managers, in order to capture crucial insights on PCC.

In exploring the concept of PCC, a qualitative approach also enables a comprehensive investigation of how factors found in a LTC setting may influence residents’, family members’ and staff members’ understanding. Qualitative methods provide individuals with the freedom to express themselves (Clow & James, 2014). Given the current lack of universal understanding of PCC in existing literature, qualitative data collection enabled exploratory discussions of both tangible and intangible variables that would have been difficult or impossible to capture using quantitative measures. In addition, this approach facilitates effective communication with older adults living in LTC who, due to physical impairments, may be unable to read or write (Barrett & Kirk, 2000). Using qualitative methods was therefore inclusive and adaptable for members of the target population which included residents who were visually impaired. Furthermore, the use of a qualitative approach is informed by previous research studies similarly examining the

perspectives of residents, family members and staff members in a LTC setting (Harrison & Frampton, 2017; Kiljunen, Kankkunen, Partanen & Välimäki, 2018; Helgesen, Larsson & Athlin, 2013; Coughlan & Ward, 2007; Train, Nurock, Manela, Kitchen & Livingston, 2005).

Data collection: focus groups. Focus groups were chosen for this research study as a method to collect qualitative data from a range of participants on a specific topic (Nyamathi & Shuler, 1990). Focus groups are useful to explore the attitudes and perceptions of individuals for various purposes, including conceptualization (Knafl & Howard, 1984; Krueger & Casey, 1988). While the use of focus groups in research emerged out of marketing, organizational research and community development, Rosaline (2008) notes that today, focus group methodology has evolved as a stand-alone method used by researchers across disciplines for their unique ability “to illuminate group processes and the way in which meanings and even action plans are developed and refined through interaction” (p. 19).

Focus groups provide unique insight into the dynamics among group members in active discussion, including the progression of debate, levels of agreement or disagreement and the temporal sequence in which new ideas are introduced (Reed & Payton, 1997). Participants are also able to explore and clarify their perspectives in comparison to other group members (Kitzinger, 1995). Interaction among focus group participants can be leveraged to investigate how individuals’ patterns of thinking evolve and why they hold the perceptions and ideas they do (Kitzinger, 1995). In addition, focus groups are a valuable opportunity to observe and understand communication methods (e.g., humor, teasing, anecdotes, arguing), which may illustrate important findings not captured with more structured qualitative approaches (Kitzinger, 1995).

Researchers note there is established face validity in focus groups, defined by Nyamathi & Shuler (1990) as “the degree to which a procedure really measures what it is supposed to

measure” (p. 1284). However, caution must be paid to the generalizability of findings as they are reflective of a group perspective among a specific set of individuals (Reed & Payton, 1997).

Focus groups were an optimal approach since the aim of this study was to explore participants’ perceptions on a topic that lacks a standard definition across the literature and in practice. In a focus group setting, these participants were able to prioritize the questions or issues that are important to them and therefore participate in guiding the discussion (Kitzinger, 1995). Given that members of the target populations (i.e., residents in LTC and older adults) are socially marginalized, a group discussion worked to attract individuals who may be otherwise intimidated by a one-on-one interview format and provide encouragement for those who may have felt they have nothing to contribute on the topic of interest (Kitzinger, 1995). Furthermore, focus groups facilitate an open forum for residents in LTC who may be resistant to voice criticism for fear it will impact the care they receive (Kitzinger, 1995). In seeking the perspectives of multiple populations (i.e., residents, family members and staff members) focus groups also facilitate data collection from more participants than would have been possible in individual interviews, given timeline restraints.

To cultivate an environment in which participants would be able to speak freely, a separate focus group was planned for each four participant types (i.e., residents, family members, direct care providers and managers). Homogeneity in focus group members is important to establish cohesiveness and counter inherent power imbalances (Nyamathi & Shuler, 1990; Reed & Payton, 1997; Kitzinger, 1995). In addition, conducting multiple focus groups on the same topic of interest with different groups allows for triangulation of the data through cross validation of the findings (Reed & Payton, 1997; Nyamathi & Shuler, 1990). Triangulation of the dataset was thus utilized in this study by conducting focus groups with four different participant types.

Sample. Purposive sampling was used to recruit participants within each focus group. A purposeful sample aims to involve participants who are adequately informed on the topic of interest (i.e., person-centred care), and are both available and willing to participate (Palinkas et al., 2015; Creswell & Plano Clark, 2011; Bernard, 2002; Spradley, 1979). Inclusion criteria for participants included i) residents who currently reside at the facility, ii) family members who have or had a family member living at Brookfield and iii) managers and direct care providers currently employed at the facility. Exclusion criteria for participants included residents with i) a diagnosis of dementia and ii) hearing or speech impairment. Residents and family members were not required to be a dyad in order to participate.

All participants were recruited from Brookfield. All family members, direct care providers and managers were invited to participate. Residents identified by Brookfield to be capable of participating and from their experience, or from participating on the residents' council, had an adequate understanding of the care practices at Brookfield, were approached to participate.

Recruitment process. Participants were recruited using recruitment flyers (Appendix C). Eligible family members and staff members were contacted by email by a familiar professional at the LTC residence with an electronic recruitment flyer. Family members and staff members were asked to contact the researcher directly to indicate their interest in participating. Once contacted, the researcher obtained verbal consent over the phone and informed them of the scheduled focus group date and time. Eligible residents were approached in-person by a familiar professional and informed about the study. Interested residents were identified to the researcher, who obtained written consent (Appendix D) in-person prior to the focus group. Focus groups were scheduled in collaboration with each participant group type and arranged on a date that was

convenient for the majority of interested participants for each participant type. Focus groups were conducted at Brookfield for participant convenience, particularly residents, many of whom are unable to independently leave the site due to physical limitations. Four focus groups were conducted in-person at Brookfield; one with residents, one with family members, one with direct care providers and one with managers.

Focus groups were led by one facilitator (KY), who was knowledgeable in the area of interest, to direct the discussion without biasing responses (Hisrich & Peters, 1982). Semi-structured focus group scripts (Appendix E) were used to guide the discussion with open-ended questions. An adapted script was used for the different participant types in order to include questions specific to their role at the facility. Scripts were developed by the facilitator based on findings from the literature, and reviewed for input and approval by the thesis supervisor. Scripts were also reviewed by a staff member at Brookfield to elicit feedback on the wording used in the questions to ensure terms and context, such as titles of legislative acts, would be understood by participants. Revisions were made based on feedback to produce the finalized scripts. All focus groups were audio-recorded to ensure accuracy.

Study procedures. Focus groups were conducted during a two-week period in April 2019. A total of 27 participants (five residents, six family members, eight direct care providers and eight managers) participated in respective focus groups. Each focus group lasted approximately one hour. A continuous effort was made to engage all participants in the discussion in each focus group to manage potentially overly dominant individuals (Reed & Payton, 1997). Member checking was performed throughout focus group discussions to confirm findings interpreted by the facilitator (Kidd & Parshall, 2000). A research assistant was present to address interruptions or distractions among the group as well as document field notes, non-

verbal communication, and the order of speakers to facilitate data analysis (Nyamathi & Shuler, 1990; Kidd & Parshall, 2000). Immediately after each focus group, an audit trail was developed by the facilitator and included in the documentation of reflections and field notes. In addition, the facilitator and research assistant debriefed immediately following each focus group to compare interpretations on points of agreement, dissent or potential coercion (Kidd & Parshall, 2000).

All participants completed a demographic form (Appendix F) prior to focus group participation to capture variables across the sample. For residents, demographics included gender, length of time on resident council and length of time in LTC. For family members, demographics included gender, length of time on family council, and length of time with a family member living in LTC. For staff members, demographics included gender, current employment title, length of time in current role, length of time working in senior care, length of time working in healthcare, membership of a regulated healthcare professional body and employment type at Brookfield (i.e., full-time (FT), part-time (PT) or casual).

Data analysis. A qualitative descriptive approach was used to examine the data set. A qualitative descriptive approach is a method of examining data outside of the confinements of established theoretical or philosophical frameworks (Sandelowski, 2000). By reducing the interference of assumptions that underlie interpretative frameworks, a researcher is more readily able to closely examine the meaning in the results (Sandelowski, 2000). Qualitative descriptive studies are noted as especially useful to answer research questions that are relevant to practitioners and policy-makers (Sandelowski, 2000).

Focus groups were transcribed verbatim and the data analysis was completed using deductive content analysis. Cross coding was applied to enhance discrimination between categories and varying participant perspectives, and to monitor the influence of group interaction

on individual responses (Kidd & Parshall, 2000). In the first step, transcripts were reviewed individually and initially coded for narrative units (i.e., larger data excerpts that include stories with comments, questions or elaborations from group members) to capture the perspectives of multiple speakers on one discussion point (Kidd & Parshall, 2000). Next, each transcript was coded line by line to abstract substantive content (i.e., what participants actually said) (Kidd & Parshall, 2000).

Coding was an iterative process, focusing on each question or issue separately, to identify emerging categories among narrative units and substantive content (Nyamathi & Shuler, 1990; Kidd & Parshall, 2000). Transcripts were then reviewed together to draw comparisons across the data set and contribute to validating preliminary categories (Nyamathi & Shuler, 1990). Findings were further validated through reassessment of dominant findings one week after the initial analysis was conducted (Nyamathi & Shuler, 1990). Detailed attention was paid throughout the analysis to the presence of conformance, censoring, coercion or conflict avoidance among participant responses (Kidd & Parshall, 2000). Transcripts were also reviewed by the thesis supervisor to compare the original data to the refined categories across the dataset.

4.0 Results

Participants

A total of 27 (five residents, six family members, eight direct care providers and eight managers) participated. Demographic information collected from participants is presented in Tables 1 to 4. Across all four groups, the majority of participants in each focus group were female. The majority of participating residents had lived at Brookfield for six months or less, whereas the majority of family member participants reported having a family member in LTC for a substantially longer time frame as the average length of time was approximately four years. The majority of participating direct care providers were either PSWs or RPNs, along with one RN participant. This participant group is reflective of a typical staff mix in Ontario LTC homes, as most direct care is provided by PSWs and RPNs. Overall, participating managers had a significant amount of experience working in the health care sector as the average was over 13 years. Managers had additionally worked in their current role at Brookfield for an average of just over eight years.

Table 1. Resident Demographics

Participant	Gender	Length of time living in LTC (months)	Length of time on residents' council (months)
1	M	< 1	0
2	F	6	0
3	F	3	3
4	F	6	0
5	M	2.5	0
Mean	–	3.7	0.6
Range	–	< 1 – 6	0 – 3

Table 2. Family Member Demographics

Participant	Gender	Length of time with family member in LTC (years)	Length of time on family member council (years)
1	F	8	6

2	F	7	4
3	M	3	1
4	F	5	0
5	F	2.25	1.33
6	M	1	1
Mean	–	4.4	2.2
Range	–	1 – 8	0 – 6

Table 3. Direct Care Provider Demographics

Participant	Gender	Role	Employment Status	Length of time in current role at Brookfield (years)	Length of time working in senior care (years)	Length of time working in healthcare (years)
1	F	PSW	FT	14	14	14
2	F	RPN	FT	6	9	9
3	F	PSW	FT	15	15	15
4	F	PSW	FT	15	15	15
5	F	RPN	FT	16	16	41
6	F	RN	FT	5	8	5
7	F	RPN	Casual	0	0	2
8	F	RPN	FT	13	20	27
Mean	–	–	–	10.5	12.3	16
Range	–	–	–	0 – 16	0 – 20	2 – 27

Table 4. Manager Demographics

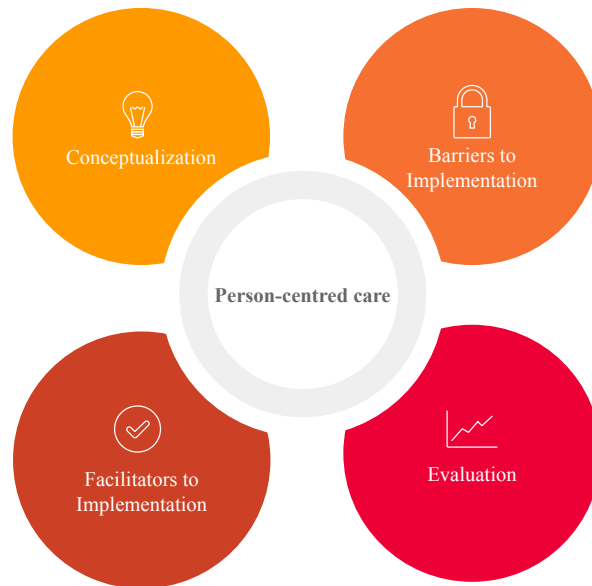
Participant	Gender	Employment Title	Employment Status	Length of time in current role at Brookfield (years)	Length of time working in senior care (years)	Length of time working in healthcare (years)
1	F	RPN	FT	< 1	12	15
2	F	PSW Manager	FT	3.5	10	10
3	F	Nursing Resource Coordinator	FT	< 1	6	6
4	F	Director of Nursing	FT	8.5	10	11
5	F	Director of Resident and	FT	16	16	41

		Family Services				
6	F	Scheduling Coordinator	FT	1.5	6	6
7	F	Environmental Services Manager	FT	5	5	5
8	M	Restorative Coordinator	FT	15	18	18
Mean	–	–	–	8.3	12.6	13.3
Range	–	–	–	< 1 – 16	5 – 18	5 – 41

Main Results

The data were analyzed and organized into four broad categories: 1) conceptualizing PCC in practice, 2) barriers to implementing PCC, 3) facilitators to implementing PCC, and 4) evaluating the practice of PCC (See Figure 2). These categories will be discussed below. As the perspectives of direct care providers and managers largely aligned across categories, findings of those two focus groups will be presented together. The perspectives of residents and family members will be discussed separately. Speakers will be identified in focus group excerpts by the following abbreviations: direct care provider (DCP), manager (M), family member (FM), resident (R) and facilitator (F).

Figure 2. Main Qualitative Results



Conceptualizing PCC in practice.

Direct care providers and managers. All direct care providers and managers expressed familiarity with the term PCC at the beginning of each focus group. PCC was most commonly conceptualized by direct care providers and managers as a “*philosophy*”. In particular, one manager emphasized: “*You got to see it as a philosophy cause it’s not task-focused. It’s not about getting the job done at the end of the day*”. Both groups linked the practice of PCC at Brookfield to the “*GentleCare philosophy*” commonly described as “*routine flexibility*” in resident care. GentleCare was further explained by one of the direct care providers as: “*If a resident doesn’t want to get up at seven o’clock, then it’s GentleCare. They don’t have to*”. Discussing PCC as a philosophy was intertwined with a role for top-down implementation. One manager explained that right from the beginning, when the facility opened, person-centredness was adopted as a philosophy and was described as follows: “*When we first opened, when we first started, it was taking on – it was special care, who was our managers, and they had that wonderful philosophy of care*”. Direct care providers similarly identified the top-down

promotion of a PCC philosophy at Brookfield as illustrated by the following exchange during the focus group:

DCP8: It's [Brookfield]'s philosophy, too

DCP4: Yeah, it's a philosophy, yes

DCP8: And it's promoted by management

DCP6: Yeah, it's great

In addition, participants frequently highlighted the resource demands of delivering PCC which they linked to the need for a *"top-down approach"* that started at the manager level. This common thread in the focus group discussion was captured in the following quote by one of the managers: *"It has to come from the top-down because you – you have to afford the staff enough time and the ability to do it"*. Direct care providers echoed this sentiment in discussing support to provide PCC for residents as evidenced by the following focus group excerpt:

DCP2: Your management

DCP4: Management plays a big part

DCP2: Like, this is their philosophy – yeah

Participants were asked to identify characteristics of PCC in practice. Both direct care providers and managers described PCC as *"individualized"* care that reflected residents' *"needs"*, *"wants"* and *"choices"*. One manager described PCC as: *"Very individualized based on their culture and their past history and experiences and family history"*. Direct care providers equated PCC as *"kinda like a care plan"* which was described as: *"centred around [residents'] needs"* and *"goals"*. As one direct care provider noted: *"Everyone is unique, their care plan should be unique to them"*. Another direct care provider highlighted: *"Well, it's [the care plan is] important too because there's conflict between what they [residents] want and what [the]*

Ministry wants". Care plans were discussed as a tool to accommodate for residents' preferences in daily routines that differ from policy standards, as one direct care provider noted: *"If it's in the care plan, that's okay"*. A manager further highlighted the role of care plans in PCC with the following statement: *"Doing care plans around exactly what [residents] want it to be"*. Another manager described delivering PCC as: *"Doing what we can to individualize the plans for each individual person"*.

In their attempts to clearly describe what PCC looked like in practice, direct care providers and managers appeared to perceive person-centredness as an innate element of providing care. Reflecting on their flexibility in daily routines to accommodate for residents' preferences, the following discussion emerged among direct care providers:

DCP8: I don't think we know any other way, actually

DCP6: Yeah, you have to be [flexible]

DCP4: You have to be, yeah. You wouldn't survive (laughs)

DCP1: These are humans that we're dealing with, not robots (laughter)

Managers echoed the sentiment that PCC is potentially implicit within care providers, illustrated in the following excerpt:

M4: Yeah, you have a calling

M8: Yeah

M5: You have a calling, absolutely

M2: Person-centred is in you

One manager elaborated to say: *"You can force the – that you're wanting to give them [residents] choice and stuff but, if you don't actually feel it and actually believe in it, you're not really going to do it. You're not gonna do everything you can"*. Another manager also agreed

with this sentiment and stated: *“You can teach somebody how to do the tasks, you can’t teach somebody how to care”*.

In a discussion about defining PCC, direct care providers and managers additionally spoke to the important role of staff and resident relationships. Forming close relationships with residents was seen as a given with PCC as *“you become their [residents’] family”* as one direct care provider commented. A manager additionally acknowledged with pride: *“I have staff upstairs who hug the residents, you know, kiss them, to go above and beyond”*. The following dialogue among managers is further illustrative of an acceptance of staff members taking on a role that invoked more than the delivery of care services, but rather fulfilling functions that may otherwise be fulfilled by family members for residents:

M5: We have a resident on fifth floor that is public guardian trustee, family don't come to visit. So, we have staff that have taken over. They celebrate every birthday, they buy her clothes, they buy her gifts, she's... more of a childlike state, and she's impaired but
[interrupted by M4]

M4: They take her to the movies

M5: They take her to the movies. But, they will bring in Barbie doll cakes for her, sparkly shoes, sparkly sweaters

M4: We had a big party for her for the royal wedding

M5: Royal wedding, and made her the princess

M4: They brought tiaras for everybody on the floor and stuff

Participants were also asked about their perception of changes at a policy level that promoted a shift towards PCC in LTC. Both managers and direct care providers noted past use of physical restraints such as *“bed rails”* and residents being *“restrained to a chair”* as well as

“chemical restraints”. Both groups indicated that a policy shift that enforced minimal restraining (chemical or physical) of residents was a significant change in practice. One direct care provider explained it as: *“readjusting... especially our way of thinking”* and a manager described the shift as: *“a big one”* and *“a major turning point”*. The significance of not restraining residents was linked to an increased risk of harm for residents, as described by one direct care provider as follows: *“It was scary for us because we didn't want our residents to fall. We wanted them to be safe”*. Both managers and direct care providers noted the implications included respecting residents’ choices despite risk of harm, which altered their perception of their roles as staff members in LTC. This change in policy that lead to major practice changes is represented in the following quote by a manager:

The restraints was a big one cause at the time, that one was very difficult to wrap your brain around because it was the idea that we weren't here to protect the resident, we were here to allow them to make their own choice – good or bad. Even when we knew better than it was a bad choice. We still had to let them make it because it was their choice and that was hard. That was a big, big change in the long-term care facility. Cause it just – everything followed from that. Everything that you looked at and made a choice about was more based on, okay, they're going to make their own choice and it's not our decision to influence. It's just to be here and support it.

In defining PCC philosophy, these participants believed there was a link between having to navigate an increased risk for residents, with the implementation of policy on minimal restraints, and residents’ rights in LTC. Participants asserted residents *“have the right”* not to be restrained, as illustrated in the following excerpt among direct care providers:

DCP 4: They [residents] have the right to fall

DCP 2: Yes, that's what it comes back to. Residents have rights

DCP 6: Yeah

DCP 1: They have the right

DCP 4: They have the right to fall

DCP 1: To put themselves at risk

Participants additionally discussed the role of family members in characterizing PCC in the LTC facility. One direct care provider described PCC as: *“Including families in the care of the residents because that's a big part of residents' lives”* and one manager reaffirmed this common sentiment with the following quote: *“It's not just caring for the resident anymore, it's a whole family”*. Family involvement was further outlined in the context of the policy shift to not restraining residents. As staff members interpreted not restraining residents to be in line with PCC, they expressed the challenge of navigating conflicting family members' expectations, as represented in the following discussion among managers:

M5: A lot – a lot of families don't agree, right?

M8: No

M5: [Families think] that they [residents] should come in here, they should be locked up and they should be safe

M4: They should be restrained to a chair

M5 Chair, yup. And that's the end of it

M4: So, they don't fall

This group discussed in detail the numerous challenges that direct care providers and managers face while balancing the role of family members in the delivery of PCC with the

prioritization of respecting residents' choices, which may not be in alignment. This is illustrated in the following discussion during the direct care providers' focus group:

DCP6: Like, try to incorporate as much [family input] as you can, like within reason

DCP7: Yeah

DCP6: Within reason for sure

DCP1: Especially if the resident's not as cognitively with it

DCP1: If the resident's cognitively aware and able to tell you, it's based on what they want, and sometimes families have a really hard time with that too

DCP2: Mhm

DCP8: Yeah

DCP1: Because, they have an idea in their head of what their family member needs or wants. But then...

DCP3: It's not always the same!

Navigating family members' preferences that differ from residents' was explained by one direct care providers as: *"I'll be like well, I think it's in so and so's best interest if we did it this way"* and *"Remember, it's not about what you want, really, like, it's about what's best for your mom or dad"*. Managers additionally acknowledged family member involvement as implicit in providing PCC as one manager highlighted: *"It's not just caring for the resident anymore, it's a whole family"*. Managers noted the ongoing challenges of incorporating family members' expectations of care by explaining it as: *"not easy"* and *"a lot of time on the phone!"*.

Family members. The majority of family members (three out of five) had no previous knowledge of the term PCC. Of the two participants that did, one identified PCC as a

“philosophy” and the other reflected on previous work experience: *“I worked in a general hospital for 31 years and the last 10 years, I guess, patient-centred care’s been the big, big buzzword”*. Participants were asked what came to mind in conceptualizing the term PCC. Family members noted the importance of meeting residents’ needs through the process of care planning, described by one participant as: *“You need to know each patient or resident or whatever, very, very well and then the care plan would be planned based on what those needs were”*. Additional components of PCC depicted by family members included a consistent caregiver, as one participant described: *“A caregiver, like PSW, that looks after the same patient all the time”* and a coordinated approach across providers, stated by another participant as: *“Very team-oriented, like, everybody has to be on the same page and everybody has to know the patient”*.

All participants shared that they previously or presently had family members at Brookfield living with dementia. This prompted a discussion including the following quote, which is representative of a belief among family members that PCC must be inclusive of residents’ families:

I am using the concept [of PCC] to recognize that the family member is part of the person-centred care. I’m the one who knows the best of what my mom needs. So, whether they ask her or ask me, doesn’t matter to the definition. I mean, obviously, I am truly, 100% trying to help my mom. So, whatever I answer would be the same as – consistently what mom would need, right? So, I use the definition of person-centred for my mom who’s got dementia, as my response as well.

Participants further discussed the importance of family member involvement in *“advocating”* and *“to ensure the personal touch”* and identified communication as an additional element of PCC, described by one participant as:

If you ask me what I would like from a – for a person-centred, from the doctor level and that, I want better communication. I want to know when he's coming in, I want to be there so I can hear what he's thinking. I want to have input into it.

Another participant highlighted this group's emphasis on the need for effective communication by stating the following: *"communication can go a long way, when – when everybody's on the same page"*.

In defining what they did not perceive PCC to be, family members raised concerns about the practice of giving residents living with dementia choices. This was explained by one of the participants as: *"[Staff members] insist that they have to give the patient a choice when the person trying to... has no – has no ability to really make that choice. So, I have – I have a bit of a problem with that"*. Another family member stated: *"Giving her choice might confuse her. So – so, that might not be person-centred, either. If it's truly person-centred, you don't give her choice"*.

However, family members also provided case examples of their conflict with providing residents' living with dementia choices, including the topic of food and dining. Participants noted that *"[residents] have to be offered these two choices of food"* which raised concern among family members as a resident may refuse to select one. One family member reflected on their experience to highlight this challenge for implementing PCC for those with dementia:

What I've said or asked is that don't give a choice. Don't give a choice. Say, this is what [food] we have today... and she can say, no, I don't want that. And then you can maybe say, well, just have a piece of toast and jam? Okay, I'll have that. So, but not to start off with a choice, because that's not what her brain is going to understand.

Family members further discussed their concern around choices, illustrated in the following excerpt:

FM6: They try to give her a choice about everything, which, like, do you want to get up today? No... you see? And that's...

FM4: Don't ask her!

FM2: Yeah. We're getting up now!

FM4: Yeah, exactly.

FM6: Exactly, and that's what I – I have said

FM2: We're just wearing this, yeah

FM: I've tried to say that many times, don't ask my mother or you'll get an answer
(laughs)

FM6: Exactly

Family members additionally spoke of case examples of PCC at Brookfield in the area of recreational programming, as highlighted by one participant: *"They're probably the best example [of PCC] in this facility"*. Family members illustrated their perception of recreational staff as person-centred in that they know residents well and know what they like, as highlighted in the following quotes from different participants: *"He loves [name of restaurant]... so they put his name down every time. They don't even ask me"*, *"They all know him really well and they know which a... an outing to sign him up for"*, and *"They are so focused on him and his needs and what – what's worked and what hasn't"*.

One family member provided an example of cultivating a sense of value for a resident living with dementia:

They let him deliver the mail because he can read the name and he can look at the numbers on the doors and deliver the mail. Not alone, but with somebody. And so, he thinks he works here because he does that. And they let him go out and work in the garden when they're planting. So, that gives him a feeling of value.

Family members conceptualized PCC as inherent within a healthcare setting and embodied within care providers themselves. Describing their reaction to the purpose of the current study one family member said: *“I thought, why would somebody write about this? (laughter) Cause isn't that a given?”*. The same family member reflected on previous work experience in healthcare to note: *“Most of us that work in healthcare, we're there to help people, we take an interest in people and you get to know people and make things happen for them”*. Another family member highlighted that providing PCC *“takes a special person”* and further expanded: *“If you hire the right people, the people who have it [PCC] ingrained in their behavior and their actions, then you're going to have a person-centred care facility”*.

When asked about changes in LTC in support of PCC, the topic of the minimal restraints policy was raised. While family members associated this change with an interpretation of PCC at a policy level, the majority of them expressed that they were not accepting of the removal of restraints, as illustrated by one participant:

They don't have medical restraints or seat belts or bed rails, or... I mean, people are left in beds with a mat on the floor, if they fall out of the bed. I think it's over the top, the – the restraint restrictions.

Family members further expressed dissatisfaction with interventions replacing physical restraints and the incongruence with a person-centred approach from their perspective:

FM1: But, they've got a buzzer connected so if they fall – because the buzzer

falls to the floor

FM2: But it's – they're still falling!

FM1: I know they are

FM5: And bones are broken before anybody gets there

FM2: So, that's a big change I've seen

FM5: Yeah

FM4: And that's a... to me, in reverse of person-centred

Residents. All residents who participated in the focus group indicated no previous knowledge of PCC. When asked about what came to mind after hearing the term, one resident replied: *“someone who looks after you”* and another resident said: *“a nurse”*. A third resident stated: *“individualized care”* which garnered agreement across participants. However, residents struggled to further conceptualize the term PCC directly. Early on in the discussion, a resident expressed a desire to be living at home *“because I have a front step, there's a dog, there's flowers, there's trees, there's friends”*. This prompted the facilitator to ask residents what elements of PCC were important to them in a LTC environment, which resulted in a much fuller discussion.

Residents responded by outlining aspects of their life at Brookfield they appreciated as well as things they felt were lacking. One resident expressed an appreciation for family relationships: *“I'm glad they let my brother come... he brought his dog for the first time, who I haven't seen in a long time but no, it was good to see my family here”*. The same resident highlighted the importance of *“good care”* which they defined as *“how they look after you, how they don't hurt you, and... I don't know, just good care!”*. Two residents echoed a desire for access to outdoor space, illustrated in the following quotes: *“I wish there was more freedom for*

me to move around. To go outside” and; “The only thing that I miss is a backyard. We don’t have a little place to go out”.

In addition, residents spoke about the desire for independence and freedom as one participant said: *“I’m kinda despondent about losing my independence”*. The same participant later noted: *“I wish I could walk to the library cause I’m able to, and enjoy the library. I wish, in some cases, I – I had more independence and could use it but right now, I’m – I have to stay on this floor. I don’t know any escape routes yet”*. Another resident reflected on the experience of feeling confined to one floor at the facility, as doors and elevator access are accessible only to those with a key: *“Walking [to] the end of the hall and the other end of the hall! That’s it. And I don’t have a key! So, I – I don’t have a key. I can’t go anywhere... I’m like in a box! I have no keys”*.

Another topic discussed by residents that they viewed as an important aspect of PCC was food preferences and their experience of dining at Brookfield. One resident reflected on limited food options and stated the following: *“It’s a small thing for us but when you put it on 30 or 60 people, you know, it’s not a small thing anymore. It’s something that people have had all their lives until maybe they’ve come into a situation like this and then they think, oh, why can’t I have this? I had it at home”*. In response, another resident expressed the great satisfaction derived from a food request being met: *“I told [the dietitian] it’d be nice to have multi-grain Cheerios. Well, today I got them!... And it was absolutely delicious!”*. Participants spoke about a negative experience of dining at meal times, as described below:

We are complaining all the time – the food is cold or it’s not enough. You know, like the day before yesterday we have a stuffed chicken and – and just a few tables were served and the girls just start – we don’t have enough. And they want to cut the portions. And

the chicken is like this and if you cut it, you end up with a piece like this... (laughter) you know and I says no way, I want the whole piece. Not because I need it but because I want them to open their eyes and open their ears. The same with the... hair – all the hair lying in the food.

Two other participants echoed concern for the quality of food service:

R1: Don't have your hair drooping down in the – or eating behind the counter!

R3: Yes, they're doing that

R1: And eating while serving

R3: Yes

The same two residents further expressed their dissatisfaction with meal times, with one participant noting: *"You want this to be a safe place. So, the kitchen staff should follow kind of a protocol that would enable that and it's not really happening on our floor here. You go to McDonald's, they wouldn't allow you do to what they do here!"*. The second resident highlighted long wait times: *"I want my coffee with my breakfast. I don't want it tomorrow, you know, so I get up and I serve myself now"*.

The topic of social interaction was raised spontaneously by residents throughout the focus group discussion about PCC. As mentioned above, one resident wanted to be back home in part because of *"friends"* and further noted: *"I can't – I can't pick the people in the – the facility but, I can pick my friends"*. A different resident noted the positive presence of social interaction: *"in [Brookfield], I have friends, I talk"*. Another participant reflected on socializing as a method of coping with boredom: *"I have good mess mates, [R4's] one of them. And we have good humor and fun and that helps to break up monotony and stuff like that"*. The same participant also

highlighted: *“I’d like to see more mental stimulation... like... discussions. Mental games, to keep me alert. Cause then I can talk to [R4]”*. Nearing the end of the focus group, the same resident raised the topic of social interaction again, as illustrated in the following excerpt:

R1: That’s one of the points I want to talk to, is that on my floor there’s only about two men I can relate with...

F: Meaning there’s not a lot of men?

R1: At sort of a mental level... I think they have a men’s club or whatever but it’s once a month. Maybe they have to interact with different floors and have more men who evolved, like, talking about certain topics... to keep us sort of young at heart, kind of!
(laughs)

In discussing elements of care that are important, residents frequently reflected on the adjustment of coming to live in LTC. One resident was adamantly against living at Brookfield in stating *“I just don’t want to be here at all”* and *“I don’t feel that I should be here”*. The resident indicated a loss of control in the decision to come to LTC: *“I haven’t been in my house... since January. I don’t think that’s fair. My kids have arranged it and I disagree because I had a budget and now my budget’s blown!”*. Another resident relayed a struggle towards acceptance of moving into LTC: *“I’m still tense about leaving a situation I’ve been in for seventy years. So, it’s kind of ironic... I had no – I knew I was on a list, but I had my 70th birthday and the theme was – you’re over the hill! (laughter) And I am! I didn’t like that a bit”*. The same resident went on to say: *“My own theory of how I looked at it – struggling with it – was this should be called the last resort! (laughter)... Either the last resort or the last resort! It depends on how I feel about it”*. A third resident relayed a more positive acceptance of living in LTC out of necessity:

In here, I have friends, I talk, I eat on-time. At home, I cannot do it because my husband's work and I there by myself all the time. And I got a problem that I fell down all the times, like, my stability's very bad. So, I have to be here. So, but I don't find this place bad. I like it to living here

Residents also highlighted negative perceptions of LTC before coming to live at Brookfield, often reflecting on family members' experiences, as one resident noted: *"I'm thinking about my grandmother and my mom, it wasn't such a hot – the places they were in. They have to sit there in wet pants and whatever"*. One resident commented on LTC as the last option for a loved one: *"My mother had multiple sclerosis, there was nowhere to go to her because the beds in the hospitals around the area were full, right? So, we have to take her to an old age home"*. Another conversation among residents explicitly highlighted the perception of LTC as a place to die:

R4: I had a brother-in-law living with me because he wasn't able to do things for himself because it's a stroke. And he say, if I have to go to a nursing home, I die. He – all the time, he said that. And after that I said, if you don't behave, I'm going to put you in a nursing home (laughter)

F: Why do you think he said that? If he goes to a nursing home, he's gonna die?

R4: Because people see it going to a nursing home it's like a, go there to die

R2: Yeah, I heard that too

R3: Mhm

R4: It is the last home, but...

R3: Yes, it is, yes

Barriers to implementing PCC. There was consensus across all four focus groups that a shortage of staff and an associated lack of funding posed major barriers to providing PCC at Brookfield. However, to illustrate the differences in experiences of these barriers, family member and resident focus group findings will be presented separately from direct care providers and managers.

Direct care providers and managers. Direct care providers identified the need for more staff “*to provide the care that we want to provide*”. A high care ratio of residents to staff was highlighted as a challenge in meeting the needs of all residents, as illustrated below:

DCP1: I look at it as, and I know that this is sometimes a bad way to look at it, but if you look at daycare, where they are five to one ratio for little people, and then you've got us who are like 10 or 11 to one, and these are full grown adults that you need to get ready and have them going

DCP6: It's insane

Direct care providers additionally noted their inability to meet standardized time requirements per resident with limited staff:

DCP6: It used to be 15 [minutes]

DCP1: Now, it's down to 12 minutes per resident

DCP2: That's all you get

DCP1: To get them ready and up

DCP6: That's not realistic

Participants described the implications of varied levels of need among residents that results in inequitable delivery of PCC in the face of limited time and staff:

DCP6: We have some residents that take 30 minutes

DCP5: We have one that takes an hour!

DCP8: 12 minutes to get...

DCP6: And then other people are suffering

Direct care providers further illustrated how a staff shortage can prohibit catering to individual preferences in daily routines, reflecting on experiences in other LTC facilities:

DCP3: I actually worked at a facility, they were getting people up starting at four in the morning

DCP4: Yeah!

DCP3: To make sure everybody was up on time for breakfast

Managers echoed staffing limitations as a barrier to person-centred LTC, as one participant stated: *“In order for us to implement person-centred care the way we would like to, we would need to... more staffing”*. Discussion among managers focused more on system level issues, including a shortage of PSWs in Ontario’s LTC sector:

M4: Lately, it's – it's more and more of a struggle with like the PSW shortage in Ontario

M6: Just trying to get someone in. It doesn't matter really who it is. It's not their normal person...

M4: It's a challenge

M6: Just getting someone in

Managers explained that in order to compensate for the *“PSW shortage”*, Brookfield hires PSWs from external agencies, which additionally impedes the delivery of PCC:

M4: The care's never the same. There is no person – person-centred care with agency use

M8: Yeah, I agree. You're just getting someone in to cover the job

M4: You're lucky if you get the care done (laughs)

Managers addressed the low rate of pay for PSWs as a contributor to present and future shortages across Ontario:

M4: I worry about, we talk about person-centred care, I worry about our generation, we end up in long-term care because nobody wants to be PSW anymore. Nobody wants this job anymore. And is – there's less and less people

M2: PSWs don't get paid enough... not for the demands that they have now

Managers further acknowledged the intersecting issues of limited staff and funding in meeting the needs of residents, as one participant stated: *"They're [residents are] more and more demanding, higher and higher needs, and our funding is pretty much stagnant. So, it is becoming harder"*.

Family members. When asked about the necessary conditions to support PCC, one family member replied: *"The only way I think that [PCC] can happen is if there's the money to have a lot of care given for every patient. And that's not realistic"*. The same family member highlighted: *"You know, like, we all want champagne care for beer dollars or whatever that phrase is, right?"*. Two family members reflected how a lack of staff at Brookfield drove them to hire additional PSW support to meet the needs and preferences of their loved ones, represented by one participant's experience below:

FM2: That's why I hired a person to come in every day because I knew my mother would be very upset, the way she looked, you know, how she – it was the most important thing to her, sadly, is how she looked and what everybody – how everybody perceived her to look

FM1: That's pretty important

FM2: Well, there's a lot of other things that are more important but because that was important to her, I hired somebody. And then now, she's bathed every day and she has... earrings on and her clothes match. And I know that she would be really happy about that. They don't have time to do that here

FM4: They don't have time, no

FM2: And that's patient focused cause that would be very, very important to her. So, I have to pay for it

Residents. With regard to elements of PCC, residents identified a lack of staff members and associated funding availability as barriers to having some of their needs and preferences met. In a discussion of the desire for more opportunities for independence to leave Brookfield, the following exchange emerged among residents:

R1: I think what you're – what it's looking like – is that they need a lot more staff

F: Okay

R3: Oh, I think they got lots of staff!

R1: I don't think they do

R4: No

R1: No

R3: No?

R1: They need lots more staff

R3: Do they?

R1: That could have – that I go to the library with, cause I know it's not gonna happen

The one resident that disagreed, however, later illustrated an example of a staff shortage during meal times: *“They – they take the girls off the floor, you know, this one girl, she’s going crazy trying to serve everyone! She can’t serve everyone!”*. The intertwined levels of staffing and funding was also introduced in the discussion, in the context of a lack of government funding available to meet staffing demands:

R5: One – one thing we have to be careful of is suggesting all these changes and additional super – supervision, is that we want better facilities for the residents. But we must remember that someone's gonna have to pay for it

R3: Exactly. That's true

R5: Can’t just say I want a PSW to go with me to [the grocery store] or to WalMart or something... somebody’s got to pay for that PSW

Facilitators to implementing PCC. The need for increased staffing as a facilitator to providing PCC was discussed in as a key factor in all four focus groups. Direct care providers, managers and family members additionally discussed the important role of education in supporting the implementation of PCC.

Direct care providers and managers. When asked about tools to assist in delivering PCC, a direct care provider replied: *“More education! Cause the more education that we have... more knowledge is power”*. Direct care providers additionally spoke to the importance of education when their perception of PCC differs from family members:

DCP1: Another thing is, and I know this doesn't get spoken of a lot but, difficult families.

Because sometimes it's very easy to deal with the resident but the families are extremely

difficult. And it's because sometimes lack of understanding. So, I think more education on a family's side would be very beneficial

DCP6: Yeah

F: So, educating the family on...? What would you like to educate them on?

DCP1: Combination of things

DCP6: I think just acceptance of what's happening

(Collective: Yeah)

DCP6: I think there's a lot of –

DCP2: Supporting their loved one

DCP1: What – what level they're at

Managers echoed the importance of providing education for both residents and family members, illustrated in the following quotes: *“Everybody needs their own education when they come in”* and: *“We have to constantly educate everyone”*. The use of education from a manager perspective focused on navigating the prioritization of residents' choices, as one manager expressed:

A lot of what we do, too, is educating the residents. We don't place high demands on them, but we know what their capabilities are, what their deficits are, we try and educate... to help them make, not better choices, but the choice they want to make.

Another manager highlighted the use of education for family members in response to a resident refusing to eat: *“It's educating the family at that point in time as to why they're doing that, why they're not doing it. Could this be the end of life?”*. Managers additionally noted ongoing education for direct care providers, as one participant stated: *“If there's something that comes up, then we do... on the unit in-services and we'll go up and educate the staff”*. Managers

also reflected on their role to educate members at the executive level of administration at Brookfield on the importance of resident choice, as the following quotes illustrate: “*You try to educate on all the things that you're gaining from it*” and: “*There’s a lot of teaching*”.

In resolving difficult and newly encountered situations at Brookfield, managers said this is where education for themselves, direct care providers and family members was crucial. One example was discussed in the context of a relationship between two residents living with dementia: “*We – myself, [name] went to education by Dr. [name]... we had a whole day on sexuality and dementia. So then, going there, learning, coming back here...* ”. The same manager further highlighted: “*It was educating them [family members] and educating the staff*”. Education was highlighted as helpful to establish a sense of shared understanding among staff and family members, and as a reference for similar scenarios in the future.

A second example arose around medical assistance in dying (MAID), as one manager explained:

We had education. We had some residents that we're wishing to do that themselves. We had concerns from some staff that didn't agree with it. But, we wanted all staff to be educated on it. So, they understood the resident side as well because again, it was their choice. And so, that was offered to all staff and families. So, that everybody understood. In this example, educating staff members was critical to alleviate concerns and promote residents’ choices in the delivery of PCC, including relatively novel situations like MAID.

Family members. From the perspective of family members, a role for education arose in discussing the delivery of PCC at Brookfield. Family members discussed their efforts advocating for the perceived needs and preferences of their loved ones, illustrated by one participant as follows: “*I had to do a lot of education and a lot of strong advocate – advocacy and it took*

about three months – three to four months for it to finally click”. Participants highlighted examples of educating staff members in instances where they disagreed with the care approach. The following is an example of this with several family members discussing their experiences related to their loved one not wanting to get out of bed in the morning:

FM6: There's so many ways, like, and I've discussed this with the PSWs, and I said, there's so many ways that you don't have to make that choice for them. You could say, for instance, what you want to wear today?

FM1: Yup. Let me help you

FM6: And so yeah, that's – not even asking them, if they want to get up

FM4: Yeah, or do you want to wear red or blue? As opposed to, do you want to get dressed?

With the following quote, one participant encourages other members of the focus group to seek education from staff members to address elements of care they do not perceive as person-centred:

If you don't understand something, send some emails and ask somebody to provide some education about what's going on and what the options are, and so on. And the communication can go a long way, when – when everybody's on the same page.

Family members reflected on the role of family council specifically, with one family member noting: *“There's two things, I think that, that we probably do very well and that's advocate for everybody, and then we try to educate families”*. A general lack of knowledge acknowledged by family members prompted one participant to suggest educating other families through the family council: *“This would be a fabulous topic for a seminar at some point, would be what is this [PCC] and to get input from family members”*.

Evaluating PCC in practice.

Direct care providers and managers. When discussing how they evaluate PCC at Brookfield, these participants talked about the accreditation process as illustrated in the following quotes; *“Quality improvement, we do all that. It’s ongoing”*; *“Well, through the accreditation, I think... it’s evaluated”*. MOHLTC inspections were noted as another method of evaluating PCC, as one direct care provider described: *“They want to know that if we’re providing that GentleCare, it’s in the care plan and that, oh, this person gets up, like they’re late riser, like, oh, I saw that in your care plan. That’s great”*. Managers also reflected on the experience of inspections as well: *“They come in with a list of 40 residents and they interview – the ones that are possible – they interview those residents. From the residents’ response, is what triggers what they’re going to look at”*. Another manager described the process as: *“They come in and watch the residents. Has the resident got all the things they need in life? Are they happy? Are they well taken care of? And if they are, then they assume all the other stuff – like the staff was doing their job. Yeah, so it is in itself resident focused”*. Other managers commented on the inspections as: *“very person-centred”* and *“very individualized”*.

Another tool discussed to evaluate PCC was surveying of residents and family members. As one direct care provider highlighted: *“They have resident satisfaction surveys that they do... which gives them a chance to – them and their families, a chance to have a voice”*. One manager noted the role of positive feedback, including survey results, as a measure of PCC:

When you get constant positive feedback – you get positive feedback at your care conferences, you get positive feedback face to face, and you get positive feedback at your

surveys, then that's saying in a picture as a whole, that you're doing something well.

You've got to be reaching that person-centred care.

The role of resident and family councils was additionally explored in a discussion of evaluating PCC. Direct care providers listed councils in a discussion of evaluating PCC, however, no elaboration on specific roles or effectiveness ensued. Meanwhile, managers engaged in a debate around the theorized role of family and resident councils in PCC at Brookfield:

F: So, leading into the family and resident councils. How do you see their roles in directing care or providing feedback on care, making it more person-centred, do you see them – those councils as having a role in that?

M5: Yup

M4: Not really

M2: Yes, they do! (laughter)

M4: They support us. But if we waited for them to – to make those little decisions that Affect everyday life, we would be waiting forever.

M2: I don't think we're waiting for them to make decisions

M5: Make decisions

M2: I think there's – they –

M4: Support – support

M2: Support and, their suggestions or concerns come forward and then we have to address those concerns, and look outside the box to see you know, what can we do? What can't we do? How can we work together to support that whole topic?

One manager described the role of the resident council as:

The residents' council is supposed to be more making that public area more like everybody's home. So, what – you're supposed to represent how does the majority of the people on that unit feel this public area should be more like their home.

The same manager further described family council as: *“Somewhat representative of the family because these are the children of the people living here”*. However, managers further deliberated the role of family council as an effective feedback tool to evaluate care:

M8: Sometimes they're [family members are] just there for their own agenda

M4: Yeah

M5: Yes

M8: I want the place to be the way I like it

M5: Yup, yup, yup

Managers additionally highlighted the evaluation of PCC using quality indicators, as one participant said: *“If we have low pain, low depression, low... or – or improving incontinence, you know, we are addressing those issues and doing what we can to individualize the plans for each individual person”*. Once again, developing individualized care plans was linked to practicing PCC. Another participant touched on capturing the absence of PCC indicated in resident behaviour: *“If you're just task-focused, you get in, you get them done, you get them out, they're going to ramp up and have behaviors, right?”*.

Managers recognized PCC as *“really hard to measure”* and *“subjective”*. In the discussion of quality indicators, one manager stated: *“The quality indicators are – you're – you're showing what your home's doing, but you're not showing what you're doing in control A or control B. You're showing how your homes doing to all the other homes, assuming that we all have the same general population, which we... we can't”*. It was further acknowledged that

aspects of PCC may be largely intangible in practice and thus, hard to evaluate, as one manager described:

You may look like you did nothing yet, you know, you were doing lots of things for this person. You're in there for 20 minutes, and then you come out, what did you do? Well, I don't really have anything to chart about, but I did seem to do an awful lot.

Family members. When asked about how to evaluate PCC in practice, family members acknowledged the process of accreditation Brookfield undergoes, described by one participant as: *“They’ve got 360 some items, I think, isn’t it? That they check off and... interview people”*. MOHLTC inspections were additionally highlighted as one participant noted: *“There’s the inspectors that come in”*. Addressing surveys as a method of evaluation, a family member explained: *“I know there’s somebody at the other end that’s looking for this information, that’s going to be of some use to them. So, I sit down, and I do it [the survey] with my mother”*.

However, the effectiveness of survey completion was debated:

FM3: We do have some of these surveys, [name of manager] comes back, and she does report what the results are and our minute taker here puts the results into the minutes and they’re – they’re accessible to the families if they have...

FM4: But, has anything changed from that? Have they created any...?

FM3: I – [interrupted by FM2]

FM2: That’d be a question for [name of manager], I guess

FM3: I – I think they have

Family members additionally touched on opportunities for feedback:

There’s little boxes around the place that if you have a comment about something, you can write it out and drop it in there. You can send an email or phone or talk with the

different people. So, there's all kinds of different factors, if you will, where this information comes in.

Residents. Discussing methods of evaluating care at Brookfield, residents were prompted about survey completion. The majority of residents engaged in the discussion and expressed a lack of awareness or participation in surveys:

F: I've heard here that you have residents' surveys, so surveys that you fill out about things that are happening. Has anyone filled one of those out before?

R3: No

R1: Nope

F: Never seen one?

R1: No

F: Never heard of one?

R4: I see them but I don't remember

In addition, residents identified instances in which the resident council served as a method of indicating requests, specifically in the domain of food preferences: *"I'm sure it's [the council is] helping the – the diet – dietician – I'm sure it's helping her to know that she can order what we want"*. However, another resident expressed concern for whether or not topics discussed at resident council meetings were effectively communicated to staff: *"Like, I thought it was – when you're on the council – it's almost like an ad-hoc committee. If you go, you're on it! I didn't know that! Like... so I went once and they had a lot of good ideas but maybe they – somebody should come – like this gentleman was saying, more communication is better"*.

5.0 Discussion

This research used qualitative case study methods to explore how PCC is understood and translated into practice in a LTC setting (Brookfield). Findings revealed both overlapping and differing perspectives among residents, family members, direct care providers and managers across four categories in discussions of PCC: conceptualization, facilitators, barriers and evaluation.

When conceptualizing PCC, all participants across the four focus groups agreed that it included the provision of individualized care for residents. While residents did not engage further in directly conceptualizing PCC, the other three participant groups did. PCC was understood similarly by both direct care providers and managers, however, family members articulated a diverging perspective. Family members did not perceive that certain standard care practices (e.g., limited use of restraints) at Brookfield were person-centred, which was in conflict with the understanding of PCC expressed by direct care providers and managers.

There was consensus across the focus groups that understaffing acts as a major barrier to meet the preferences of residents in the delivery of PCC. While residents did not discuss facilitators in practice, family members, direct care providers and managers acknowledged multiple uses for education in the promotion of PCC. Direct care providers and managers spoke to educating residents and family members on policies of care, as well as ongoing education initiatives to train staff members in the promotion of PCC. Family members additionally highlighted education, noting their role to convey information on residents' needs and preferences to staff members. As some participants were members of the family council, education was also outlined in the role of the council to educate other families about care expectations.

Discussions of how to evaluate PCC included direct care providers and managers outlining accreditation processes, MOHLTC inspections and feedback obtained through surveying as well as resident and family councils. Family members echoed the role of accreditation, MOHLTC inspections and providing feedback including through survey completion. However, family members were skeptical of the effectiveness of providing feedback and questioned if any change had occurred as a result. Residents briefly spoke about the role of residents' council to provide feedback specifically in relation to food preferences. Residents expressed a lack of awareness or participation in surveys. These findings highlight an inconsistent perspective on methods and effectiveness of evaluating PCC.

Conceptualizing PCC – Tensions in Policy

Family members demonstrated a conceptualization of some aspects of PCC outside of what they presently observe in practice. Their awareness of the impact of policy on practice contributed to their ability to define what policy enforced elements they did not perceive as person-centred. Blanket policies they observed such as not restraining residents and providing residents with choices were of particular concern to them. Not restraining residents was perceived as the *“reverse of person-centred”* in light of the increased risk of harm for residents who fall. In addition, providing a choice for residents with dementia was perceived negatively, if for example, the result was a resident choosing not to get out of bed in the morning or not to eat a meal.

Both the removal of restraints and providing residents with a choice are included in the Residents' Bill of Rights under the LTCHA. The Legislative Assembly of Ontario (2010) outlines the LTCHA to state that “every resident has the right not to be restrained” and “every resident has the right to have his or her lifestyle and choices respected” (p. 1). Direct care

providers and managers described the implementation of the LTCHA in 2010 as a shift in their approach to care towards person-centredness. They described their acceptance of respecting residents' choices and the minimal use of restraints as components of person-centred practice. With the LTCHA, their role changed from shaping residents' decisions to mitigating any risk incurred by residents' autonomous decision-making. As this understanding of PCC is in alignment with legislation governing the Ontario LTC sector, resulting tensions arise in purporting the LTCHA as a guideline for person-centred practices.

As a policy tool, legislation effectively demands compliance to standardized practices (Ferlie, Lynn & Pollitt, 2005). However, standardization is largely absent from the literature on PCC reflecting the nature of the approach to involve individualized care that meets various needs and preferences (Brownie & Nancarrow, 2013; Clarke et al., 2017; Jones, 2011; Koren, 2010). Direct care providers and managers spoke about providing choice, withholding restraints and developing individualized care plans as consistent practices at Brookfield. As regulations in the LTCHA, these practices mirror an interpretation of PCC that Bowers, Nolet, Roberts & Esmond (2007) call "adapting a standard treatment or care plan to individual needs" (p. 9). This approach is aligned with the regulated environment of LTC which requires facilities to comply to legislation in order to remain operable with a license. However, the ability to respond to individual needs and preferences that fall outside, or are in conflict with, standard procedures is challenged. Family members' interpretations of PCC highlighted this in multiple cases where they perceived the standard practice as not meeting the individual needs of their loved ones. For example, the requirement that all residents eat meals in the dining area did not meet the needs of a resident refusing to leave their room.

In addition, desired elements of LTC outlined by residents such as access to outdoor space, the ability to participate in activities away from Brookfield and increased food options are examples of resident-identified preferences. These preferences may be viewed as integral to respecting a resident's 'right' to have their lifestyle and choices respected. However, the lack of availability of these options to residents demonstrates that residents' 'rights' are operable only in parallel with the remaining regulations of the LTCHA. For example, the Legislative Assembly of Ontario (2010), outlines that the LTCHA states that doors must have locks to "restrict unsupervised access to those areas by residents" (p. 1). This regulation clearly challenges a resident's 'right' to choose to freely walk outside. This regulation can be additionally viewed as the prioritization of safety, which is pervasive in LTC and often equated with quality care (Kane & Kane, 2001). However, as participants noted, other regulations such as the removal of restraints result in an increased risk of falling and potential harm for residents, and thus prioritizes resident autonomy over their safety.

An additional point of contention with resident autonomy was family members' desired level of involvement in decision-making in dementia care. Family members disagreed with providing residents with dementia the choices they observed in practice, which is in conflict with direct care providers and managers' understanding of PCC rooted in the LTCHA. In addition, it is in contrast to the literature on PCC for those living with dementia which argues for individualized care that promotes independence for all, regardless of diagnosis (Alzheimer's Society, 2011; Crandall, 2007; Mead & Bower, 2000; Ryden, 1992; Williams, 1990). While research shows that choices can be a stressful and challenging situation for those with dementia (Iyengar & Lepper, 2000; Reutskaja & Hogarth, 2009), there is enduring support for autonomy in dementia care (Fetherstonhaugh, Tarzia, Bauer, Nay & Beattie, 2014). Fetherstonhaugh et al.,

(2014) state that additional research findings indicate “it is clear that people with dementia can and do make decisions” (p. 210). Care guidelines that endorse a person-centred approach developed by the Alzheimer’s Society (2011) instruct caregivers to “respect the right to self-determination of all persons with dementia no matter where they are in the disease progression” (p. 16).

Family members supported an active and engaged role for themselves to ensure PCC in dementia care, which was illustrated in their efforts to advocate against practice standards they perceived as not person-centred. Family member involvement in decision-making in person-centred dementia care is additionally endorsed across the literature (Alzheimer’s Society, 2011; Edvardsson, Fetherstonhaugh & Nay, 2010; Helgesen, Larsson & Athlin, 2013), although their perceptions have been scarcely explored (Helgesen et al., 2013). In a study by Helgesen et al. (2013) family members of LTC residents with dementia “considered their participation to be almost essential to reach the goal of well-being” (p. 1677). These findings are in line with the current study as family members expressed a similar desire for a high level of involvement, sometimes to the point of acting as substitute decision-makers.

Both resident autonomy in dementia care and the extent to which family members may be involved in decision-making is lacking in the policy regulations of the LTCHA. The only regulation concerning dementia care mandates additional training for staff members (The Legislative Assembly of Ontario, 2010). As the LTCHA appears to guide direct care providers and managers’ interpretation of PCC, it is not surprising that standards of practice are extended to those with dementia. Furthermore, it is clearly on the shoulders of the organization to implement alternative care standards. The regulations under the LTCHA pertaining to family member involvement in care include participation in meetings and care planning as substitute

decision-makers or when designated (The Legislative Assembly of Ontario, 2010). The latter suggests that greater participation of family members in dementia care may be possible compared to what the participants in this study experienced. However, if the Residents' Bill of Rights is applicable to all residents, there is clearly a potential conflict in respecting residents' choices if they differ from those of a family member, even when in the role of substitute decision-maker.

In summary, the movement to respect resident autonomy in LTC as part of a broader change in culture is in competition with both safety and family member involvement in care planning (Kane & Kane, 2001). These opposing forces are reflected in the translation of PCC into practice at Brookfield whereby direct care providers and managers appear to attempt to strike a balance. However, the voices of residents and family members expose the gaps in the implementation PCC due to the legislated standards that Ontario LTC facilities must adhere to. Thus, direct care providers and managers at Brookfield are inhibited from fully implementing PCC as they are confined by policy standards that may contradict the expressed wishes of residents and their families.

Conceptualizing PCC – Resident Perspective

While both direct care providers and managers were familiar with the term PCC and could discuss its role in practice, the majority of family members and all residents who participated in this study had no previous knowledge of this term. An absence of awareness and knowledge of the term 'PCC' prompted the discussion with residents to revolve around their experience of LTC and what was important to them in a LTC setting. Previous research investigating the preferences of LTC residents is limited (Kane & Kane, 2001). While residents

in this study did highlight positive aspects of their lives at Brookfield, the group dialogue was focused on unmet needs or preferences. Residents emphasized a desire for outdoor space, independence to leave Brookfield, improved dining experience and access to more food options, as well as more “*mental stimulation*”, and social interaction. In line with some of these results, Abbott et al. (2018) found that choosing what to eat, going outside and leaving the facility to do things were among the top ten ranked preferences of LTC residents. Additional findings have echoed the preference for the ability to leave the facility and experience the outdoors more often (Kane & Kane, 2001; Harrison & Frampton, 2017).

In the context of food and dining at Brookfield, the majority of residents expressed their dissatisfaction. Food in LTC settings is frequently a medicalized aspect of daily life, geared towards meeting nutritional standards (as per government and accreditation requirements) at the expense of residents’ preferences (Savishinsky, 2003; Hung & Choudhury, 2011). The experience of eating is noted to serve both emotional and social needs in addition to physical subsistence and often carries an association with social relationships, personal identity, comfort and care (Hung & Choudhury, 2011; Evans, Crogan & Shultz, 2005). Limited food options were indicated as “*not a small thing*” and appeared to be an ongoing issue requiring resident advocacy.

Residents equated the displeasure of dining at Brookfield with long wait times to receive their food, poor quality, a shortage of food and subsequent reduced portion sizes. One resident’s reaction to a reduced portion at a meal was to demand the full portion because: “*I want them to open their eyes and open their ears*”. Previous research has additionally echoed this tendency of LTC staff to neglect the psychosocial needs of residents while dining (Gibbs-Ward & Keller, 2005; Moore, 2004; Pearson, FitzGerald & Nay, 2003; Schell & Kayser-Jones, 1999; Sydner &

Fjellström, 2005). Residents' experiences at Brookfield highlight both a limited number of staff members available to effectively serve residents on-time as well as an absence of consideration for residents' subjective experience of feeling overlooked.

Additional preferences of residents in the current study highlight the importance of supporting residents' psychological and social well-being in person-centred LTC. A social relationship among two participating residents was outlined positively in the discussion as a form of coping with "*monotony*" and the longing for more social interaction was clear. One resident was eager to socialize with others on different floors and another expressed an absence of social connection at Brookfield. In a study by Coughlan & Ward (2007), building friendships was identified as important among LTC residents. Other researchers have previously documented the imperative role of social relationships for residents (Aller & Van Ess Coeling, 1995; Ford, 1995; Bickerstaff, Grasser & McCabe, 2003). While personal and medical care needs appeared to be met for residents in the current study, their psychosocial well-being was seemingly not prioritized. Furthermore, the gap between what is available to residents in LTC and what they desire in their daily lives clearly signals a disconnect in the provision of PCC at Brookfield.

Capturing the perspectives of residents in this study highlighted the current incongruence of PCC as an ideal at a policy level and the reality of daily life in LTC. Residents readily discussed what it is like to live in LTC and what was taken away from them upon entering an institutionalized environment. The desire for increased food options, more outdoor space and more independence are all examples of practical changes that residents identified as important. Thus, a critical lesson in responding to the current state of a person-centred approach in LTC lies in developing a lens of PCC that prioritizes the practical needs and preferences of residents over a theoretical debate.

Conceptualizing PCC – Tensions in Policy and Practice

While some practices of PCC at Brookfield were seemingly grounded in the policy regulations of the LTCHA, additional findings highlighted a perceived incongruence with policy and a person-centred approach. Direct care providers and managers conveyed PCC as an innate trait within care providers as it “*takes a special person*”, “*is in you*”, and requires “*a calling*”. Family members additionally recognized practices they associated with PCC such as meeting individual needs and preferences as “*a given*”. This finding was echoed in the discussion with residents as one participant conceptualized the term to be synonymous with “*good care*”. Li & Porock (2014) state that “PCC seems to carry with it a moral authority which means that the PCC movement has gained traction based on the approach simply being seen as ‘the right thing to do’” (p. 1413). Participants’ perceptions of PCC as an inherent element of care suggests the approach may be considered ethically right. This perception contributes to the previous finding that providing instruction on the delivery of PCC may not result in consistent translation into practice (Li & Porock, 2014). This points to the concern of the effectiveness of utilizing policy and practice guidelines as vehicles to implement PCC in a top-down approach.

Conceptualizing PCC – Tensions in LTC

The incongruence of LTC as a PCC setting was acknowledged and discussed by residents. The move to LTC was associated with a loss of control and independence, described by one resident as “*the last resort*”. Reflecting on the experience of LTC for their loved ones in the past, residents regarded LTC as a last option, the last home and a place to die. Similarly, previous research examining residents’ perceptions of LTC has identified the conveyed experience of waiting to die (Coughlan & Ward, 2007). Residents’ perspectives of LTC

highlighted moving to the care setting did not meet their preferences but rather, was a decision made out of necessity or for one resident, a decision made by family members. These findings make it difficult to align LTC and the care provided as a person-centred approach for these residents.

As a care setting born out of an institutional framework, LTC appears to be fundamentally misaligned with PCC. Capturing residents' perceptions in this study highlights the importance of examining LTC within the institutional framework from which it emerged and continues to exist. Despite calling them LTC 'homes', institutional routines are apparent in the historically task-based system that prioritizes efficiency and control over the resident experience (Kane & Kane, 2001). In addition, LTC facilities are scarcely innovative in their physical structure. The hospital-like model of a central nursing station and resident rooms side by side along the hallways is still prevalent. Kane & Kane (2001) state that LTC is "an institution that bears no resemblance to ordinary life" (p. 117). Person-centred LTC denotes a movement away from an approach to care that perpetuates residents as tasks to complete rather than humans of value in need of care and support to lead meaningful lives. However, LTC has remained stagnant as it continues to be strictly regulated by the government and continues to warehouse residents in large-scale institutional buildings. Similarly, the experiences of residents in the current study highlighted the persistent challenge of transforming an institution into a 'home'.

Barriers to Implementing PCC – Tensions in Policy and Practice

Understaffing was linked to time and resource constraints as a result of a high number of residents assigned to each staff member. Direct care providers stated the MOHLTC expectation of "*12 minutes per resident*" as unrealistic with a typical ratio of one PSW to 10 residents. Across Canada, a direct care provider is responsible for the care of an average of 19.6 residents

(Daly, Banerjee, Armstrong & Armstrong, 2011). Inadequate staffing is discussed across the literature, and has been highlighted as an ongoing issue in LTC for over 20 years (Gibson & Barsade, 2003). The resulting overburdened staff members, in combination with increasingly complex care needs of residents in recent years can be linked to high rates of staff turnover and burnout across the LTC sector (Bowers, Esmond & Jacobson, 2003).

The findings in this study were similar as family members, direct care providers and managers acknowledged the challenges of both complex resident needs and frequent staff turnover at Brookfield. Managers additionally cited a provincial wide PSW shortage that leads to the hiring of direct care providers from external agencies to fill the gaps. Managers noted these workers lack the training and education to provide PCC and were viewed as providing low quality care. Previous research indicates that both organizational and system level support must be in place to enable person-centred staff and resident interactions (Li & Porock, 2014). While managers at Brookfield indicated their supportive role to build capacity for PCC through resource distribution, the associated barriers of funding and staff shortages was corroborated by both family members and managers. As the case of Brookfield demonstrates, system level support to compensate an increased number of staff is clearly lacking and prohibits the delivery of equitable PCC for residents.

Facilitators to Implementing PCC – The Role of Education

Education was identified as the core facilitator for the implementation of PCC by family members, direct care providers and managers. Direct care providers and managers spoke to the necessity of education for staff members, families and residents in the provision of PCC and in order to work towards a mutual understanding of care expectations. Family members depicted

their role in educating staff members on residents' needs and preferences, as well as care they perceived to be person-centred for their loved ones. In addition, family members highlighted education as a tool to enhance other families' knowledge of PCC in the future.

Education is frequently cited as a strategy for the implementation of PCC (Ghogomu et al., 2017; North West Local Health Integration Network, 2016; Coleman, Fanning & Williams, 2015; RNAO, 2015; Li & Porock 2014; Wodchis, Williams & Mery, 2014; Central Local Health Integration Network, 2013; Saint Elizabeth Health & Yee Hong Centre for Geriatric Care, 2013; HQO, 2012). Educating healthcare providers on communication, empowerment and shared decision-making has been shown to promote the delivery of PCC (McMillian et al., 2013; Saint Elizabeth, 2011; RNAO, 2015). A component of training to enhance communication, ensuring providers are educated on residents' needs and preferences, is of paramount importance (Coleman et al., 2015). In addition, education on PCC must be seen as an ongoing initiative to support long-term culture change (Coleman et al., 2015). Thus, a prevalent recognition of a role for education among these study participants is promising. However, there are clearly gaps in education efforts illustrated in the conceptualization of PCC by family members and residents compared to direct care providers and family members.

Residents expressed a total lack of knowledge of the term PCC and the majority of family members did as well. Thus, an initial gap is apparent and showcases an area for improvement within Brookfield to provide residents and families with education on the implementation of PCC. In addition, the priorities in a person-centred approach identified by family members that conflicted with the understanding of direct care providers and managers demonstrates a second gap in establishing shared understanding. Direct care providers and managers both identified PCC at Brookfield as a "*top-down*" approach supported by management. Thus, there is a

necessary role for management to both promote and inform all of those with a stake in the care provided at Brookfield, including residents and family members.

Evaluating PCC – Tensions in Policy, Practice and Family Member Expectations

The common methods of evaluation cited by direct care providers, managers and family members of accreditation and MOHLTC inspections can be characterized as top-down approaches. MOHLTC inspections are historically ingrained in the culture of LTC, however, managers highlighted inspections as an element in LTC that had evolved to be more person-centred. Managers described the process of interviewing and surveying residents to identify areas of the organization to examine and did highlight a shift away from an “*audit*” of staff. Direct care providers additionally described the experience of MOHLTC inspections to include monitoring of PCC in practice. However, the elements of the inspections they described were directly in line with policy regulations such as the use of care plans and providing residents with choices. Family members additionally discussed inspections as directly monitoring staff for compliance to regulations.

This finding illustrates how current methods of evaluating LTC feed into direct care providers’ and managers’ understanding of PCC as rooted in policy regulations, as discussed above. Ontario’s LTC system employs surveillance in the form of organizational inspections to ensure that homes are complying to policy standards (DeForge, van Wyk, Hall & Salmoni, 2011). DeForge et al. (2011) note such an approach to create “a kind of ‘meet these standards or else’ mentality that results in managers being blamed (and homes being sanctioned) when standards are not met” (p. 423). Thus, it could be expected for staff members at Brookfield to conceptualize PCC according to the legislative framework under which they operate and by association, identify inspections as person-centred. This discussion points to the limited

autonomy of LTC managers to define PCC and thus, conceptualize methods of evaluation beyond those that encompass compliance to policy standards.

The use of quality indicators to capture PCC in practice was a main focus of managers in discussing evaluation methods. However, within this discussion emerged evidence of practice challenges that clash with expectations of system wide quality assurance measures. One manager commented that Brookfield's falls rates were "*so high*" as a result of the removal of restraints and respecting residents' choices. The manager further explained the ongoing task of "*teaching*" executive members of administration who are "*so worried*" by fall rates and associated liability that as managers, they are "*more concerned about quality of life*".

Researchers and policy makers frequently equate PCC with quality care in health settings (Edvardsson et al., 2010). HQO revised the LTC quality indicators in 2015 (Appendix G), 10 of which are categorized as person-centred, including rates of falls among residents and use of physical restraints (HQO, 2015). Both of these indicators outwardly reflect a focus on resident safety which Kane (2001) states has become "the be-all and end-all of LTC" reinforced by regulations that support "the best possible quality of life as is consistent with health and safety" (p. 296). However, providing PCC as they conceptualized it, both direct care providers and managers acknowledged the struggle of navigating safety, especially risk of falls, as a result of not restraining residents. In contrast, family members expressed disagreement with the removal of restraints, which they did not perceive as person-centred, due to the resulting risk of falls and subsequent harm to residents. Furthermore, as highlighted previously, the residents' concrete views of what PCC meant to them, such as having food choices or being able leave their floor at Brookfield independently, are not reflected in these indicators.

As the perspectives of participants' in this study also illuminate, an expectation that low fall rates will coexist with minimal use of restraints is unrealistic. Thus, the government mandate to measure both these indicators together yields a paradoxical attempt at measuring quality of care. Furthermore, fall rates as an indicator of quality clashes with a person-centred approach as it is understood by staff at Brookfield. The source of contention between staff and family members' perspectives surrounding resident choice, the removal of restraints and the associated risk of falls is clearly compounded by the current attempts at measuring quality across the LTC sector.

Similar to the structure of MOHLTC inspections, accreditation services provide standards and survey organizations to evaluate if those standards are being met (Franklin, 2017). Organizational accreditation has become a common practice in healthcare (McCormack & McCance, 2016; Greenfield & Braithwaite, 2008). Family member, direct care provider and manager participants in this study all spoke to the organization CARF. In 2008, the CARF was introduced in Ontario's LTC sector as an external evaluator with their "Person Centered Long Term Care Community" standards (Boodt, 2008). A description of these standards includes a number of characteristics common in the literature on PCC as well as the LTCHA such as ensuring resident autonomy and choice (CARF International, 2018). CARF provides accreditation certificates for up to three years following the successful completion of their survey, which includes observation, interviews and documentation review (CARF International, 2019).

The effectiveness of accreditation to achieve improved outcomes for care recipients is debated in the literature (Greenfield & Braithwaite, 2008; McDonald, Wagner & Gruneir, 2015). In a review by Greenfield & Braithwaite (2008) of the use of accreditation across the health

sector, only one study pursued an evaluation of the impact on resident care of “recorded improvements” following accreditation. Furthermore, peer-reviewed research to inform the standards of accreditation organizations is frequently lacking (Williams et al., 2015). The elements of the accreditation process that make it an effective measure of PCC were not discussed by participants in this study. Instead, family members, direct care providers and managers appeared to mention it as part of a routine and did not explore why or how it was useful.

Theoretical Implications

Through the lens of street-level bureaucracy, front-line workers possess the autonomy to interpret policy and thus shape the process of implementation (Lipsky, 2010). PCC may be viewed as especially vulnerable to the discretion of subjective interpretation by front-line workers in light of the absence of a universally accepted definition, which is subsequently missing from legislation and other policy documents in Ontario. In the theory of street-level bureaucracy, the autonomy of front-line workers is a focal component and is often positioned to be in opposition with the efforts of managers as top-down policy administrators (Evans, 2011). In contrast, this case study demonstrated an alignment in the perspectives of direct care providers and managers. Their shared understanding illustrated a collective autonomy to influence the policy implementation of PCC despite their different roles in the organization.

The roots of direct care providers' and managers' understanding of PCC was embedded in both the LTCHA and the philosophy of GentleCare promoted at an organizational level. These foundations of shared understanding highlight an additional layer of discretion that is acknowledged in street-level bureaucracy whereby the implementation of new policies is influenced by existing ones (Evans, 2011; Lipsky, 2010). As both direct care providers and managers identified regulations of the LTCHA in their understanding of PCC, this established legislation appears to act as frequent discretionary lens through which they apply PCC into practice.

Furthermore, their understanding of PCC in the context of the LTCHA and in conjunction with a lack of awareness of subsequent legislation focused on PCC (i.e., the ECFAA and the PFA) highlights considerable discretion in policy implementation at an organizational level in LTC. In addition, discussions of the barriers to implementing PCC illustrated resource

and subsequent time restraints that impact how front-line workers are able to translate their understanding of PCC into practice. This finding is directly in line with a street-level bureaucracy perspective that time and resource availability influences front-line workers' autonomous decision-making (Tummers & Bekker, 2013).

Although not yet documented in the literature on street-level bureaucracy this case study demonstrated family members were additionally acting as street-level bureaucrats with regard to PCC policy implementation. Family members' conceptualization of PCC differed from direct care providers and managers as it was not fully aligned with regulations of the LTCHA. In addition, family members did not express awareness of a GentleCare approach in practice at Brookfield. Family members provided multiple case examples where they intervened in the care of their loved ones in an attempt to alter the practices of direct care providers in line with the LTCHA (e.g., asking a PSW to bring a meal to a resident's room). Some family members explained their suggestions of altered care practices for dementia care, such as not giving their loved ones a choice or adjusting the types of choices provided. One example was asking a resident what they want to wear that day instead of asking them if they will get out of bed in the morning. Family members therefore articulated their own autonomous role in shaping PCC in practice, with their perceptions often in contrast the policy framework of the LTCHA referenced by direct care providers and managers. These findings provide preliminary evidence for broadening the theory of street-level bureaucracy in the health sector beyond the examination of front-line workers.

However, as street-level bureaucrats, the autonomy of direct care providers, managers and family members failed to dominate the implementation of PCC in practice. While both direct care providers and managers spoke of adapting policy standards to meet residents' needs, they

also indicated the need for strict adherence to the LTCHA regulation of minimizing restraints. Their lack of discretion in restraining residents was exemplified by family members who expressed a preference for the use of physical restraints to prevent residents from falling and injuring themselves. Direct care providers and managers both advocated against this preference they heard from some family members, illustrating their compliance to the LTCHA. Threats to a facility's operation and reputation in the event of noncompliance promote adherence to policy regulations in LTC (DeForge et al., 2011), even when they may be against the wishes of family members. Staff members' compliance in this scenario may be further explained by an additional policy regulation that mandates them to respect residents' choices. In contrast, there is a lack of policy guidance on navigating family members' autonomy in resident care.

In this scenario, it is clear that the LTCHA, as an existing policy framework in LTC, may additionally act as a barrier to PCC. Compliance to policy clearly precludes the clinical decision-making of direct care providers in LTC, an accepted practice in acute care settings (Bucknall, 2013). However, a person-centred approach, as part of culture change in LTC, frequently cites autonomy and empowerment for care providers, as well as for residents and family members (Brownie & Nancarrow, 2013; Koren, 2010). In addition, reports on LTC have called for increased discretion for providers in the delivery of care (Curry & Nova Scotia Nurses' Union, 2016; Long Term Care Innovation Expert Panel, 2012). While changes at a policy level may facilitate greater autonomy for care providers, the threat of policy noncompliance is a stagnant opposing force. Furthermore, it is clear that a person-centred approach to LTC is challenged by competing priorities of safety and liability additionally embedded in legislation. As the findings of this case study illustrate, policy in LTC ensures standardized procedures that are in conflict with the autonomy of staff members, residents and their families to implement an individualized,

person-centred approach. These types of legislated standards therefore disempower these groups to mediate policy implementation as street-level bureaucrats.

6.0 Policy Implications and Organizational Recommendations

An important finding of the current study was the incongruent perspectives of residents, family and staff members on the language, concepts and practices of PCC. Residents and family members' path to understanding person-centredness diverged from that of direct care providers and managers. While residents and family members expressed an awareness of the implications of policy to shape care providers' actions in practice, they did not identify legislative regulations as proponents of PCC. In contrast, discussions of PCC and case examples provided by staff members reflected an understanding of PCC through the lens of LTCHA. Thus, it is evident that there is a lack of shared understanding of PCC as a concept and how it is translated into practice at Brookfield. This is in keeping with the literature as Gillespie, Florin & Gillam (2004) found that the variance in awareness and knowledge about PCC suggests an incomplete picture that may be failing to capture the full range of applicable characteristics of PCC in a LTC setting (Gillespie et al., 2004). In addition, a variety of terms were discussed by participants in relation to PCC, which further highlights the diversity of interpretation and the lack of clarity at a policy level (Gillespie et al., 2004). A feeling of ownership for providers and care recipients is a key element in the policy implementation of PCC (Gillespie et al., 2004). Thus, it will be important to further explore discrepancies in understanding across stakeholders.

Furthermore, exploring the views of residents, their families and providers in LTC is critical in light of the lack of clarity that follows the term in research and policy documents. As an approach to care, person-centredness was introduced by policy makers and endorsed across healthcare settings without examining the meaning of it at an individual level (Gillespie et al., 2004). Interestingly, research on PCC in practice frequently neglects to explore the perspectives of key stakeholders including care recipients and their families (Edvardsson et al., 2010). As a

study by Scales et al. (2019) illustrates, research eliciting the voices of residents and family members in person-centred LTC often focuses on implementation, without first examining how PCC is conceptualized by these stakeholders. It was clearly evident in the focus group discussions with direct care providers and managers that they truly care about the residents and families they serve, and are keen to embody PCC throughout the organization. Thus, there is an opportunity at Brookfield to initiate a group dialogue that includes residents, family members, direct care providers and managers to establish a shared understanding of PCC and develop strategies to support implementation at an organizational level.

As highlighted by participants in this study, education is one tool that could be used to improve stakeholders' understanding and facilitate the provision of PCC. Direct care providers and managers' understanding of PCC was informed by information they received outside of their professional training. In furthering the capacity for direct care providers in LTC including PSWs, RPNs and RNs, education on conceptualizing and practicing PCC for residents should be integrated into their professional training programs in colleges and universities. Additionally, it was evident that managers were frequently forced to seek out information and guidance on a person-centred approach when situations fell outside of what is included in the LTCHA. It is clear that as a policy framework to inform practice, the LTCHA does not comprehensively address the intricacies of PCC within LTC. In order to move PCC forward across Ontario's LTC sector, education for organizational stakeholders must be made uniformly accessible.

As a government regulated sector, organizational power in LTC is largely defined by legislative regulations. In passing regulations related to LTC, policy makers must be keenly aware of the restricted availability of funding to carry out changes (Caspar, Cooke, Phinney & Ratner, 2016). The potential for change at an organizational level may be stunted by a lack of

resources, which often is due to the absence of system level supports. While establishing a shared understanding of PCC across stakeholders at Brookfield is an important step, findings of the preliminary discussions captured in this study showcase the need for resources to support direct care providers to meet the needs of residents and their families in PCC. Thus, it is critical that advocacy groups and the broader public demand change across the publicly funded LTC sector in Ontario to fully implement PCC as mandated by accreditors, and envisioned by residents and their family members. The OLTCA, as well as the Registered Practical Nurses Association of Ontario, the RNAO and the Ontario PSW Association could be utilized to reach all LTC stakeholders. Collaboration among these organizations will be key to continue a conversation of PCC and move towards a universal understanding within Ontario.

For many years, the call for an appropriate staff to resident ratio that is mandated in LTC has been made by numerous stakeholders including, researchers, journalists and healthcare professionals (Curry and Nova Scotia Nurses' Union, 2016; CBC News, 2018). Understaffing is a key barrier to practice change (Donnelly & MacEntee, 2016; Curry and Nova Scotia Nurses' Union, 2016) and as reiterated by the participants in this study, is also, a significant obstacle in the delivery of equitable PCC. Furthermore, research findings have linked adequate staffing to increased job satisfaction and lower rates of burnout (Friese, Lake, Aiken, Silber & Sochalski, 2008; Kelly, McHugh & Aiken, 2011) and if mandated through legislation, there is evidence that staffing standards are effective in improving quality outcomes (Harrington, Phillips, Hawes, Schnelle & Simmons, 2015; Bowblis, 2011; Harrington, Swan and Carrillo, 2007; Lin, 2014; Mueller et al., 2006; Glance et al., 2012; Curry and Nova Scotia Nurses' Union, 2016).

The current political leadership in Ontario has endorsed 30,000 additional LTC beds over the course of 10 years (Breen, 2018). The 2019 Ontario health system report outlines key action

items in LTC to include building the capacity of the sector and reviewing admission criteria, in an effort to reduce wait times across the province and reduce crowding in hospitals (Premier's Council on Improving Healthcare and Ending Hallway Medicine, 2019). The same government states a commitment to PCC across Ontario's health sector and has reiterated their support for the inclusion of the voices of care recipients and their families (MOHLTC, 2018). However, if the government simply builds more institutions (i.e., beds) in the LTC sector without addressing staffing shortages and standardizing ratios, the implementation issues highlighted in this study and others will continue to be perpetuated (Zimmerman, 2014). A paradox emerges whereby what is mandated by policy regulations (e.g., accommodating for resident choices) is not feasible in the current LTC system riddled with understaffing and underfunding. Within this paradox, PCC is a tokenistic term that is continuously inflated at a policy level and meaningless in practice (McCance, McCormack & Dewing, 2011).

Findings from this study support the additional implication that there is a clear lack of comprehensiveness in defining quality in Ontario's LTC sector. There is a deficit in capturing the voices of residents and family members in ongoing quality assurance efforts, thus failing to align with the shift of person-centredness. The use of clinical indicators in LTC to evaluate quality of care is in line with an institutional and medicalized approach to care (Coughlan & Ward, 2007). The prioritization of these quality indicators is reinforced by MOHLTC inspections, accreditation services and most recently, the Premier's Council on Improving Healthcare and Ending Hallway Medicine (2019) health system reports. The extent of including residents in these processes is to evaluate the degree to which quality standards, developed without residents' input, are met. Thus, the current system neglects the subjective experiences of residents and their families at a provincial level. There is a lack of mechanisms in place to first,

elicit open-ended feedback and second, deliver actionable items to address concerns. The voices of care recipients act as an essential reality check on standardized observation methods of evaluation (Mead & Bower, 2000). The inclusion of dedicated efforts to qualitatively and consistently explore the perspectives of residents and families beyond a research setting supports an enhanced understanding of how PCC can be implemented cohesively in Ontario LTC homes like Brookfield. The current practice of regular MOHLTC inspections could support the collection of this qualitative data to inform a provincial level analysis of common themes in conceptualizing and practicing PCC across Ontario LTC homes. In addition, broadening the scope of inspections could facilitate an opportunity for staff to discuss their perspectives of PCC. Information sourced from these efforts could be used as starting point for determining knowledge gaps and thus, the educational needs of staff as part of the quality improvement agenda.

7.0 Limitations

This study sample may be limited in its representativeness as the researcher was not able to recruit a wide range of participants within the resident and family member population. The participating residents had lived at Brookfield for six months or less which may have impacted their responses in the focus group discussion in light of their recent transition. All participating family members previously or presently had loved ones at Brookfield with dementia, which largely informed the discussion and may impact the generalizability of their perceptions beyond dementia care. However, in contrast only one participating direct care provider worked with residents with dementia and no participating residents were diagnosed with any level of cognitive impairment. As a single case study, this research is further limited in generalizability to all LTC facilities in Ontario.

8.0 Conclusion

As a concept embedded in Ontario legislation and across policy documents, this case study provided valuable insight into the interpretation of PCC and its translation into practice at a LTC facility in Ontario. Findings demonstrated the insufficiency of efforts at public policy level to produce a cohesive understanding and implementation of PCC across Ontario's LTC sector. The findings of this study identified the LTCHA as a core guideline informing the provision of person-centred LTC from the perspective of staff members. Greater attention must be paid to clarify the association of PCC with this piece of legislation, which provided staff which justification for their actions even in the face of disagreement from residents and family members. The Residents' Bill of Rights (under the LTCHA) represents a productive starting point to begin assessing how the legislative picture of PCC can be adapted to better mirror the realities of practice.

Importantly, this case study highlighted the ironic exclusion of the resident and family member voices in the integration of PCC, a concept that is purported to be 'centred' around those receiving care. Investigating the perspectives of these groups, especially residents, is a worthwhile endeavour as current policies and practices frequently fail to meet their preferences (Kane & Kane, 2001). A comparison of the perspectives of residents and family members with direct care providers and managers suggests the need for an active dialogue and knowledge exchange to work towards establishing a shared understanding of PCC at Brookfield. In addition, the current findings suggest consideration for the role of both managers and family members, in addition to front-line workers, as street-level bureaucrats in policy implementation. Future research to expand the theory of street-level bureaucracy may generate new knowledge on the

multitude of power relationships in LTC policies and how they influence the process of implementation and thus, the care provided.

The movement of culture change in LTC presents as an ongoing process: one that requires support for all stakeholders involved (Harrison & Frampton, 2017). The key barriers of understaffing and underfunding identified by participants in this study highlight systemic issues that must be addressed at a policy level in order to inform a future of LTC that has the capacity to deliver equitable and effective PCC. Advocating at a public policy level presents the greatest opportunity for effective change that will impact the lives of a growing number of older adults and their families across Ontario.

Future research in this area would be valuable to broaden the scope of potential findings and increase generalizability. A comparison case study involving several LTC homes in Ontario exhibiting differing socio-demographics among residents, families and staff members would allow for an analysis of how various extraneous factors may influence how stakeholders interpret and translate PCC into practice.

Appendix A

Residents' Bill of Rights

(Adapted from the Legislative Assembly of Ontario, 2010)

1. Every resident has the right to be treated with courtesy and respect and in a way that fully recognizes the resident's individuality and respects the resident's dignity.
2. Every resident has the right to be protected from abuse.
3. Every resident has the right not to be neglected by the licensee or staff.
4. Every resident has the right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs.
5. Every resident has the right to live in a safe and clean environment.
6. Every resident has the right to exercise the rights of a citizen.
7. Every resident has the right to be told who is responsible for and who is providing the resident's direct care.
8. Every resident has the right to be afforded privacy in treatment and in caring for his or her personal needs.
9. Every resident has the right to have his or her participation in decision-making respected.
10. Every resident has the right to keep and display personal possessions, pictures and furnishings in his or her room subject to safety requirements and the rights of other residents.
11. Every resident has the right to,
 - i. participate fully in the development, implementation, review and revision of his or her plan of care,
 - ii. give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent,
 - iii. participate fully in making any decision concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to or from a long-term care home or a secure unit and to obtain an independent opinion with regard to any of those matters, and
 - iv. have his or her personal health information within the meaning of the *Personal Health Information Protection Act, 2004* kept confidential in accordance with that Act, and to have access to his or her records of personal health information, including his or her plan of care, in accordance with that Act.
12. Every resident has the right to receive care and assistance towards independence based on a restorative care philosophy to maximize independence to the greatest extent possible.
13. Every resident has the right not to be restrained, except in the limited circumstances provided for under this Act and subject to the requirements provided for under this Act.
14. Every resident has the right to communicate in confidence, receive visitors of his or her choice and consult in private with any person without interference.
15. Every resident who is dying or who is very ill has the right to have family and friends present 24 hours per day.
16. Every resident has the right to designate a person to receive information concerning any transfer or any hospitalization of the resident and to have that person receive that information immediately.

17. Every resident has the right to raise concerns or recommend changes in policies and services on behalf of himself or herself or others to the following persons and organizations without interference and without fear of coercion, discrimination or reprisal, whether directed at the resident or anyone else,
 - i. the Residents' Council,
 - ii. the Family Council,
 - iii. the licensee, and, if the licensee is a corporation, the directors and officers of the corporation, and, in the case of a home approved under Part VIII, a member of the committee of management for the home under section 132 or of the board of management for the home under section 125 or 129,
 - iv. staff members,
 - v. government officials,
 - vi. any other person inside or outside the long-term care home.
18. Every resident has the right to form friendships and relationships and to participate in the life of the long-term care home.
19. Every resident has the right to have his or her lifestyle and choices respected.
20. Every resident has the right to participate in the Residents' Council.
21. Every resident has the right to meet privately with his or her spouse or another person in a room that assures privacy.
22. Every resident has the right to share a room with another resident according to their mutual wishes, if appropriate accommodation is available.
23. Every resident has the right to pursue social, cultural, religious, spiritual and other interests, to develop his or her potential and to be given reasonable assistance by the licensee to pursue these interests and to develop his or her potential.
24. Every resident has the right to be informed in writing of any law, rule or policy affecting services provided to the resident and of the procedures for initiating complaints.
25. Every resident has the right to manage his or her own financial affairs unless the resident lacks the legal capacity to do so.
26. Every resident has the right to be given access to protected outdoor areas in order to enjoy outdoor activity unless the physical setting makes this impossible.
27. Every resident has the right to have any friend, family member, or other person of importance to the resident attend any meeting with the licensee or the staff of the home.

2007, c. 8, s. 3 (1).

Appendix B

Ethics Approval Documents



To: Katarina Young
Politics and Public Administration
Re: REB 2018-483: Is Long-Term Care Person-Centred? A Case Study
Date: February 5, 2019

Dear Katarina Young,

The review of your protocol REB File REB 2018-483 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2018-483) on future correspondence.

Congratulations and best of luck in conducting your research.

A handwritten signature in black ink, appearing to read "Patrizia Albanese".

Dr. Patrizia Albanese, PhD
Chair, Ryerson University Research Ethics Board

The Following protocol attachments have been reviewed and approved.

- Demographic forms 20DEC2018.docx (submitted on: 20 Dec 2018)
- Consent Form - Residents 20DEC2018 .docx (submitted on: 20 Dec 2018)
- Consent Form - Other employees 20DEC2018.docx (submitted on: 20 Dec 2018)
- Interview guide 20DEC2018 .docx (submitted on: 20 Dec 2018)
- Recruitment Script (e-mail) - Other Employees 20DEC2018.docx (submitted on: 20 Dec 2018)
- Recruitment Script (e-mail) - Managerial Employees 20DEC2018.docx (submitted on: 20 Dec 2018)
- Consent Form - Family Members 20DEC2018.docx (submitted on: 20 Dec 2018)
- Recruitment script (telephone) Family members and Residents 20DEC2018.docx (submitted on: 20 Dec 2018)
- Focus Group Script 20DEC2018.docx (submitted on: 20 Dec 2018)
- Consent Form - Managerial employees 20DEC2018.docx (submitted on: 20 Dec 2018)
- Consent Form - Family Members tracked changes 4Feb 2019.docx (submitted on: 04 Feb 2019)
- Consent Form - Family Members clean 4Feb 2019.docx (submitted on: 04 Feb 2019)
- Consent Form - Other employees tracked changes 4Feb 2019.docx (submitted on: 04 Feb 2019)
- Consent Form - Other employees clean 4Feb 2019.docx (submitted on: 04 Feb 2019)
- Focus Group Script for Family Members and Residents tracked changes 4Feb2019.doc (submitted on: 04 Feb 2019)
- Recruitment script (telephone) Family members and Residents tracked changes 3Feb2019.docx (submitted on: 04 Feb 2019)
- Recruitment Script (e-mail) - Other Employees clean 3Feb2019.doc (submitted on: 04 Feb 2019)
- Recruitment Script (e-mail) - Other Employees tracked changes 3Feb2019.doc (submitted on: 04 Feb 2019)
- Focus Group Script for Employees clean 4Feb2019.doc (submitted on: 04 Feb 2019)
- Consent Form - Residents tracked changes 4Feb 2019.doc (submitted on: 04 Feb 2019)
- Recruitment script (telephone) Family members and Residents clean 3Feb2019.docx (submitted on: 04 Feb 2019)
- Recruitment Script (e-mail) - Managerial Employees clean 3Feb2019.doc (submitted on: 04 Feb 2019)
- Consent Form - Residents clean 4Feb 2019.doc (submitted on: 04 Feb 2019)
- Consent Form - Managerial employees clean 4Feb 2019.docx (submitted on: 04 Feb 2019)
- REB response to reviewers 4Feb2019.docx (submitted on: 04 Feb 2019)
- Focus Group Script for Employees tracked changes 4Feb2019.doc (submitted on: 04 Feb 2019)
- Consent Form - Managerial employees tracked changes 4Feb 2019.docx (submitted on: 04 Feb 2019)
- Recruitment Script (e-mail) - Managerial Employees tracked changes 3Feb2019.doc (submitted on: 04 Feb 2019)
- Focus Group Script for Family Members and Residents clean 4Feb2019.doc (submitted on: 04 Feb 2019)

If any changes are made to the attached document throughout the course of the research, an amendment MUST be submitted to, and subsequently approved by the REB.

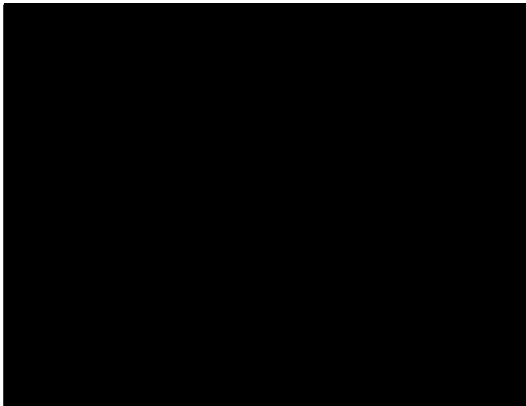


March 14, 2019

To Whom It May Concern:

Please accept this letter as confirmation that the research project titled *Is Long-Term Care Person-Centred? A Case Study* to be conducted by Katarina Young has been approved to go forward (participants can be recruited and data collection can be completed from the site).

Thank you,



Appendix C

Recruitment Materials



REB protocol number: 2018-483

This information will accompany an email that will be forwarded to potential participants from the organization. The researchers will not have a list of individuals to contact.

Hello,

My name is Katarina Young. I am a student at Ryerson University in the department of Public Policy and Administration. I am contacting you to see if you might be interested in participating in a research study.

This research is being done as part of my Masters project and my supervisor's name is Dr. Karen Spalding. The focus of the research is to explore the perspectives of key stakeholders on how person-centred care is implemented at [REDACTED]. We are interested in how employees at [REDACTED] understand person-centred care, including what components of care are important to them. We are particularly interested in how person-centred care can be adapted for the older adult population. To participate you need to be an employee at [REDACTED].

If you agree to volunteer you will be asked to participate in an in-person focus group at [REDACTED] with other employees. Your participation will involve a one time commitment of one hour.

Your participation is completely voluntary and if you choose not to participate it will not impact your relationship with [REDACTED] or Ryerson University.

The research is not funded and has been reviewed and approved by the Ryerson University Research Ethics Board. If you are interested in more information about the study or would like to volunteer, please contact Katarina Young by replying to this email or calling 416-979-5000 x3567.



REB protocol number: 2018-483

This information will be used after initial contact is made by a familiar staff member from the organization. The researchers will not have a list of individuals to contact.

Hello,

My name is Katarina Young. I am a student at Ryerson University in the department of Public Policy and Administration. I am contacting you to see if you might be interested in participating in a research study.

This research is being done as part of my Masters project and my supervisor's name is Dr. Karen Spalding. The focus of the research is to explore the perspectives of key stakeholders on how person-centred care is implemented at [REDACTED]. We are interested in how residents and family members at [REDACTED] understand person-centred care, including what components of care are important to them. We are particularly interested in how person-centred care can be adapted for the older adult population. To participate you need to be a member of the family and resident council at [REDACTED].

If you agree to volunteer you will be asked to participate in an in-person focus group at [REDACTED] with other members of the family and resident council. Your participation will involve a one time commitment of one hour.

Your participation is completely voluntary and if you choose not to participate it will not impact your relationship with [REDACTED] or Ryerson University.

The research is not funded and has been reviewed and approved by the Ryerson University Research Ethics Board. If you are interested in more information about the study or would like to volunteer, please contact Katarina Young by replying to this email or calling 416-979-5000 x3567.

Appendix D

Consent Forms



Ryerson University Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

IS LONG-TERM CARE PERSON-CENTRED? A CASE STUDY

Consent form for administrative and direct care provider employees

INVESTIGATORS: This research study is being conducted by Katarina Young from the department of Public Policy and Administration and Dr. Karen Spalding from the School of Health Services Management at Ryerson University.

If you have any questions or concerns about the research, please feel free to contact:

Katarina Young, BHSc, MA Candidate at k1young@ryerson.ca

Karen Spalding PhD, RN at karen.spalding@ryerson.ca or 416-979-5000 ext 3567

PURPOSE OF THE STUDY: You are being asked to consent to participate in a research study because you are an employee at [REDACTED]. We are interested in how employees, residents and family members at [REDACTED] understand person-centred care, including what components of care are important to them. We are particularly interested in how person-centred care can be adapted for the older adult population. A total of 25 participants from [REDACTED] are being asked to participate in this entire study. Participants must be employees or members of the family and resident council at [REDACTED] and English speaking. This research is being completed by a graduate student in partial completion of a Master's degree. The results of this research will contribute to a thesis.

WHAT YOU WILL BE ASKED TO DO: If you volunteer to participate in this study, you will be asked to do the following things:

Focus Group

You will be asked to participate in one focus group with other employees to speak about your perspective on person-centred care at [REDACTED]. The focus group will take approximately one hour and will be conducted in-person at [REDACTED] at a time that is convenient. If you no longer wish to be part of this focus group once it begins, you can withdraw at any time. All

focus groups will be audio-recorded. If you are not willing to be audio-recorded, you cannot participate in this focus group and will be given the opportunity to participate in an individual telephone interview where only notes will be taken.

You will be asked questions about your perspective on person-centred care and what person-centred care looks like in long-term care. Sample questions include:

1. How would you define person-centred care?
2. What components of person-centred care are important to you?

The study will also collect personal information that could identify you, such as:

- name;
- contact information;

This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected encrypted USB key accessible only to Katarina Young and Dr. Karen Spalding, if electronic. Research findings will be made available to participants through knowledge dissemination efforts following the completion of thesis research.

POTENTIAL BENEFITS: You will not benefit directly from participating in this study. Some people feel good about taking part in research because they like the idea of helping others. It is the hope that the results of this study will help capture the perspectives of employees, family members and residents on what person-centred care looks like in long-term care.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT: The potential risk involved in participating in this study is very low. Discomforts or inconveniences associated with participation in this study include the time commitment required to participate in a focus group. In addition, if you begin to feel uncomfortable, you may skip answering a question or stop participation, either temporarily or permanently, at any time. During the focus group, there is a risk that negative information about [REDACTED] and/or the care provided will be disclosed. This risk will be mitigated by establishing a common understanding among focus group participants that the aim of the research is not to uncover negative information but rather to explore participants' perceptions and experiences with person-centred care. In addition, participants will be asked to respect differing opinions and the confidentiality of the focus group to encourage an open discussion and reduce the risk that comments will be repeated later and possibly taken out of context.

CONFIDENTIALITY: We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this. The research team will be required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that they may come across during the duration of their research. No personally identifying information will be obtained and retained by the study team. No real names will be used in published material, pseudonyms will be assigned. While I, the researcher, will respect the confidentiality of all participant's information, I cannot promise or

ensure that other participants in a focus group will do the same. I will, however, ask all participants in the study to respect the confidentiality of all participants.

The audio-recording will be stored on an encrypted USB. Only Katarina Young and Dr. Karen Spalding will have access to the recording. The audio-recording of the interview will be typed out word for word and all personally identifying information will be removed “de-identified”. After it has been written out, the audio-recording will be securely destroyed. The written de-identified interview will be retained at Ryerson University for one year following the completion of the Masters project for which this research is being done. This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected file on a secure network accessible only to Katarina Young and Dr. Karen Spalding. You have the right to review/edit the audio-recording or transcript of the interview.

The study staff and the others listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

INCENTIVES FOR PARTICIPATION: You will not be paid to participate in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time. Your employment at [REDACTED] will not be affected in any way by whether you take part in this study. If you choose to stop participating, you may also choose to not have your data included in the study up to one year following the completion of the Masters project for which this research is being conducted. If you choose to withdrawal your data, none of your quotes will be utilized in published data. The researchers will do their best to remove your contribution from the data analysis, however, given the nature of group discussion, it may not be possible to remove everything. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigators, Katarina Young and Dr. Karen Spalding, involved in the research.

QUESTIONS ABOUT THE STUDY: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Dr. Karen Spalding PhD, RN at [416-979-5000 ext 3567](tel:416-979-5000) or karen.spalding@ryerson.ca

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

CONFIRMATION OF AGREEMENT: Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

Signature of Participant

Date



Ryerson University Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

IS LONG-TERM CARE PERSON-CENTRED? A CASE STUDY

Consent form for family members

INVESTIGATORS: This research study is being conducted by Katarina Young from the department of Public Policy and Administration and Dr. Karen Spalding from the School of Health Services Management at Ryerson University.

If you have any questions or concerns about the research, please feel free to contact:

Katarina Young, BHSc, MA Candidate at k1young@ryerson.ca

Karen Spalding PhD, RN at karen.spalding@ryerson.ca or 416-979-5000 ext 3567

PURPOSE OF THE STUDY: You are being asked to consent to participate in a research study because you are a family member at [REDACTED]. We are interested in how employees, residents and family members at [REDACTED] understand person-centred care, including what components of care are important to them. We are particularly interested in how person-centred care can be adapted for the older adult population. A total of 25 participants from [REDACTED] are being asked to participate in this entire study. Participants must be employees or members of the family and resident council at [REDACTED] and English speaking. This research is being completed by a graduate student in partial completion of a Master's degree. The results of this research will contribute to a thesis.

WHAT YOU WILL BE ASKED TO DO: If you volunteer to participate in this study, you will be asked to do the following things:

Focus Group

You will be asked to participate in one focus group with other family members and residents to speak about your perspective on person-centred care at [REDACTED]. The focus group will take approximately one hour and will be conducted in-person at [REDACTED] at a time that is convenient. If you no longer wish to be part of this focus group once it begins, you can withdraw at any time. All focus groups will be audio-recorded. If you are not willing to be audio-recorded, you cannot participate in this focus group and will be given the opportunity to participate in an individual telephone interview where only notes will be taken.

You will be asked questions about your perspective on person-centred care and what person-centred care looks like in long-term care. Sample questions include:

3. How would you define person-centred care?
4. What components of person-centred care are important to you?

The study will also collect personal information that could identify you, such as:

- name;
- contact information;

This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected encrypted USB key accessible only to Katarina Young and Dr. Karen Spalding, if electronic. Research findings will be made available to participants through knowledge dissemination efforts following the completion of thesis research.

POTENTIAL BENEFITS: You will not benefit directly from participating in this study. Some people feel good about taking part in research because they like the idea of helping others. It is the hope that the results of this study will help capture the perspectives of employees, family members and residents on what person-centred care looks like in long-term care.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT: The potential risk involved in participating in this study is very low. Discomforts or inconveniences associated with participation in this study include the time commitment required to participate in a focus group. In addition, if you begin to feel uncomfortable, you may skip answering a question or stop participation, either temporarily or permanently, at any time. During the focus group, there is a risk that negative information about [REDACTED] and/or the care provided will be disclosed. This risk will be mitigated by establishing a common understanding among focus group participants that the aim of the research is not to uncover negative information but rather to explore participants' perceptions and experiences with person-centred care. In addition, participants will be asked to respect differing opinions and the confidentiality of the focus group to encourage an open discussion and reduce the risk that comments will be repeated later and possibly taken out of context.

CONFIDENTIALITY: We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this. The research team will be required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that they may come across during the duration of their research. No personally identifying information will be obtained and retained by the study team. No real names will be used in published material, pseudonyms will be assigned. While I, the researcher, will respect the confidentiality of all participant's information, I cannot promise or ensure that other participants in a focus group will do the same. I will, however, ask all participants in the study to respect the confidentiality of all participants.

The audio-recording will be stored on an encrypted USB. Only Katarina Young and Dr. Karen Spalding will have access to the recording. The audio-recording of the interview will be typed

out word for word and all personally identifying information will be removed “de-identified”. After it has been written out, the audio-recording will be securely destroyed. The written de-identified interview will be retained at Ryerson University for one year following the completion of the Masters project for which this research is being done. This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected file on a secure network accessible only to Katarina Young and Dr. Karen Spalding. You have the right to review/edit the audio-recording or transcript of the interview.

The study staff and the others listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

INCENTIVES FOR PARTICIPATION: You will not be paid to participate in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time. Your employment at [REDACTED] will not be affected in any way by whether you take part in this study. If you choose to stop participating, you may also choose to not have your data included in the study up to one year following the completion of the Masters project for which this research is being conducted. If you choose to withdrawal your data, none of your quotes will be utilized in published data. The researchers will do their best to remove your contribution from the data analysis, however, given the nature of group discussion, it may not be possible to remove everything. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigators, Katarina Young and Dr. Karen Spalding, involved in the research.

QUESTIONS ABOUT THE STUDY: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Dr. Karen Spalding PhD, RN at 416-979-5000 ext 3567 or karen.spalding@ryerson.ca

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

CONFIRMATION OF AGREEMENT: Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told

that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

Signature of Participant

Date



Ryerson University Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

IS LONG-TERM CARE PERSON-CENTRED? A CASE STUDY

Consent form for residents

INVESTIGATORS: This research study is being conducted by Katarina Young from the department of Public Policy and Administration and Dr. Karen Spalding from the School of Health Services Management at Ryerson University.

If you have any questions or concerns about the research, please feel free to contact:

Katarina Young, BHSc, MA Candidate at k1young@ryerson.ca

Karen Spalding PhD, RN at karen.spalding@ryerson.ca or 416-979-5000 ext 3567

PURPOSE OF THE STUDY: You are being asked to consent to participate in a research study because you are a resident at [REDACTED]. We are interested in how employees, residents and family members at [REDACTED] understand person-centred care, including what components of care are important to them. We are particularly interested in how person-centred care can be adapted for the older adult population. A total of 25 participants from [REDACTED] are being asked to participate in this entire study. Participants must be employees or members of the family and resident council at [REDACTED] and English speaking. This research is being completed by a graduate student in partial completion of a Master's degree. The results of this research will contribute to a thesis.

WHAT YOU WILL BE ASKED TO DO: If you volunteer to participate in this study, you will be asked to do the following things:

Focus Group

You will be asked to participate in one focus group with other residents and family members to speak about your perspective on person-centred care at [REDACTED]. The focus group will take approximately one hour and will be conducted in-person at [REDACTED] at a time that is convenient. If you no longer wish to be part of this focus group once it begins, you can withdraw at any time. All focus groups will be audio-recorded. If you are not willing to be audio-recorded, you cannot participate in this focus group and will be given the opportunity to participate in an individual telephone interview where only notes will be taken.

You will be asked questions about your perspective on person-centred care and what person-centred care looks like in long-term care. Sample questions include:

5. How would you define person-centred care?
6. What components of person-centred care are important to you?

The study will also collect personal information that could identify you, such as:

- name;
- contact information;

This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected encrypted USB key accessible only to Katarina Young and Dr. Karen Spalding, if electronic. Research findings will be made available to participants through knowledge dissemination efforts following the completion of thesis research.

POTENTIAL BENEFITS: You will not benefit directly from participating in this study. Some people feel good about taking part in research because they like the idea of helping others. It is the hope that the results of this study will help capture the perspectives of employees, family members and residents on what person-centred care looks like in long-term care.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT: The potential risk involved in participating in this study is very low. Discomforts or inconveniences associated with participation in this study include the time commitment required to participate in a focus group. In addition, if you begin to feel uncomfortable, you may skip answering a question or stop participation, either temporarily or permanently, at any time. During the focus group, there is a risk that negative information about [REDACTED] and/or the care provided will be disclosed. This risk will be mitigated by establishing a common understanding among focus group participants that the aim of the research is not to uncover negative information but rather to explore participants' perceptions and experiences with person-centred care. In addition, participants will be asked to respect differing opinions and the confidentiality of the focus group to encourage an open discussion and reduce the risk that comments will be repeated later and possibly taken out of context.

CONFIDENTIALITY: We will respect your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this. The research team will be required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that they may come across during the duration of their research. No personally identifying information will be obtained and retained by the study team. No real names will be used in published material, pseudonyms will be assigned. While I, the researcher, will respect the confidentiality of all participant's information, I cannot promise or ensure that other participants in a focus group will do the same. I will, however, ask all participants in the study to respect the confidentiality of all participants.

The audio-recording will be stored on an encrypted USB. Only Katarina Young and Dr. Karen Spalding will have access to the recording. The audio-recording of the interview will be typed

out word for word and all personally identifying information will be removed “de-identified”. After it has been written out, the audio-recording will be securely destroyed. The written de-identified interview will be retained at Ryerson University for one year following the completion of the Masters project for which this research is being done. This information will be stored in a locked storage unit behind three locked doors if paper-based, and will be housed in a password-protected file on a secure network accessible only to Katarina Young and Dr. Karen Spalding. You have the right to review/edit the audio-recording or transcript of the interview.

The study staff and the others listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

INCENTIVES FOR PARTICIPATION: You will not be paid to participate in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time. Your employment at [REDACTED] will not be affected in any way by whether you take part in this study. If you choose to stop participating, you may also choose to not have your data included in the study up to one year following the completion of the Masters project for which this research is being conducted. If you choose to withdrawal your data, none of your quotes will be utilized in published data. The researchers will do their best to remove your contribution from the data analysis, however, given the nature of group discussion, it may not be possible to remove everything. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigators, Katarina Young and Dr. Karen Spalding, involved in the research.

QUESTIONS ABOUT THE STUDY: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Dr. Karen Spalding PhD, RN at 416-979-5000 ext 3567 or karen.spalding@ryerson.ca

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

CONFIRMATION OF AGREEMENT: Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told

that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

Signature of Participant

Date

Appendix E

Focus Group Scripts

Focus Group Script for Residents

Introduction

Hello. My name is [name]. I'd like to start off by thanking each of you for taking time to participate today. We'll be here for about an hour.

The reason we're here today is to gather your perspective on person-centred long-term care at [REDACTED].

I'm going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

I also would like you to know this focus group will be audio-recorded. The identities of all participants will remain confidential.

Guidelines for the Focus Group (i.e. Ground Rules)

To allow our conversation to flow more freely, I'd like to go over some guidelines I would like all of us to follow which are:

1. Only one person speaks at a time. This is important as our goal is to make a written transcript of our conversation today.
2. Please avoid side conversations as this can be distracting.
3. Everyone does not have to answer every single question, but I'd like to hear from each of you today as the discussion progresses and so I may take time to make sure everyone has a chance to respond.
4. This is a confidential discussion in that I will not report your names or who said what to others. Names of participants will not be included in the final report that discusses the content of this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
5. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without worrying that your comments will be repeated later and possibly taken out of context.
6. There are no "wrong answers," just different opinions.
7. The purpose of this focus group is not to elicit negative information about [REDACTED] but rather, to explore your perceptions and experiences of person-centred care. Please keep in mind that as a researcher, I am required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that I may come across during the duration of the research.

8. Let me know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.
9. Are there any questions before we get started?

Introduction of Participants

Before we start, I'd like to know a little about each of you. Please tell me:

1. Your name
2. How long have you lived at [REDACTED]

Questions

1. How would you define person-centred care?
 - a. Probes: What does person-centred care mean to you? Who does it involve?
2. What considerations are important for person-centred care of older adults?
 - a. Probe: What components of person-centred care are important to you?
3. What do you think person-centred care looks like in practice at [REDACTED]?
 - a. Probes: How would you describe a person-centred interaction between a staff member and a resident? What types of activities at [REDACTED] are person-centred?
4. What role do you think the resident council has in promoting person-centred care at [REDACTED]?
 - a. Probes: What issues are important to the council? How are these issues determined? How often does the council meet? What does the council aim to accomplish?
5. Are you aware of any changes [REDACTED] has made to implement person-centred care policies?
 - a. If yes, what types of changes and in what areas? Did efforts involve collaboration with residents and family members? Are you aware of any evaluation efforts?
 - b. If no, why do you think that is?
6. What do you think helps staff members to provide person-centred care?
 - a. Family conferences? Nursing model of care? Variation of staff members?
7. What do you think makes it difficult for staff members to provide person-centred care?
8. Are you aware of any policies in Ontario that relate to person-centred care?
 - a. Probes: If yes, which ones?
 - b. What relevance do these policies have to long-term care?
9. How do you think person-centred care can be evaluated in your organization?

Closing

Thank you for coming today and providing valuable input. Your comments have given us lots of different ways to see this issue. I thank you for your time.

Focus Group Script for Family Members

Introduction

Hello. My name is [name]. I'd like to start off by thanking each of you for taking time to participate today. We'll be here for about an hour.

The reason we're here today is to gather your perspective on person-centred long-term care at [REDACTED].

I'm going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

I also would like you to know this focus group will be audio-recorded. The identities of all participants will remain confidential.

Guidelines for the Focus Group (i.e. Ground Rules)

To allow our conversation to flow more freely, I'd like to go over some guidelines I would like all of us to follow which are:

1. Only one person speaks at a time. This is important as our goal is to make a written transcript of our conversation today.
2. Please avoid side conversations as this can be distracting.
3. Everyone does not have to answer every single question, but I'd like to hear from each of you today as the discussion progresses and so I may take time to make sure everyone has a chance to respond.
4. This is a confidential discussion in that I will not report your names or who said what to others. Names of participants will not be included in the final report that discusses the content of this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
5. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without worrying that your comments will be repeated later and possibly taken out of context.
6. There are no "wrong answers," just different opinions.
7. The purpose of this focus group is not to elicit negative information about [REDACTED] but rather, to explore your perceptions and experiences of person-centred care. Please keep in mind that as a researcher, I am required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that I may come across during the duration of the research.
8. Let me know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.
9. Are there any questions before we get started?

Introduction of Participants

Before we start, I'd like to know a little about each of you. Please tell me:

1. Your name

Questions

1. How would you define person-centred care?
 - a. Probes: What does person-centred care mean to you? Who does it involve?
2. What considerations are important for person-centred care of older adults?
 - a. Probe: What components of person-centred care are important to you?
3. What do you think person-centred care looks like in practice at [REDACTED]?
 - a. Probes: How would you describe a person-centred interaction between a staff member and a resident? What types of activities at [REDACTED] are person-centred?
4. What role do you think the family council has in promoting person-centred care at [REDACTED]?
 - a. Probes: What issues are important for the council to address? How are these issues determined? How often does the council meet? What does the council aim to accomplish?
5. Are you aware of any changes [REDACTED] has made to implement person-centred care policies?
 - a. If yes, what types of changes and in what areas? Did efforts involve collaboration with residents and family members? Are you aware of any evaluation efforts?
 - b. If no, why do you think that is?
6. What do you think helps staff members to provide person-centred care?
 - a. Family conferences? Nursing model of care? Variation of staff members?
7. What do you think makes it difficult for staff members to provide person-centred care?
8. Are you aware of any policies in Ontario that relate to person-centred care?
 - a. Probes: If yes, which ones?
 - b. What relevance do these policies have to long-term care?
9. How do you think person-centred care can be evaluated in your organization?

Closing

Thank you for coming today and providing valuable input. Your comments have given us lots of different ways to see this issue. I thank you for your time.

Focus Group Script for Managers

Introduction

Hello. My name is [name]. I'd like to start off by thanking each of you for taking time to participate today. We'll be here for about an hour.

The reason we're here today is to gather your perspective on person-centred long-term care at [REDACTED].

I'm going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

I also would like you to know this focus group will be audio-recorded. The identities of all participants will remain confidential.

Guidelines for the Focus Group (i.e. Ground Rules)

To allow our conversation to flow more freely, I'd like to go over some guidelines I would like all of us to follow which are:

1. Only one person speaks at a time. This is important as our goal is to make a written transcript of our conversation today.
2. Please avoid side conversations as this can be distracting.
3. Everyone does not have to answer every single question, but I'd like to hear from each of you today as the discussion progresses and so I may take time to make sure everyone has a chance to respond.
4. This is a confidential discussion in that I will not report your names or who said what to others. Names of participants will not be included in the final report that discusses the content of this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
5. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without worrying that your comments will be repeated later and possibly taken out of context.
6. There are no "wrong answers," just different opinions.
7. The purpose of this focus group is not to elicit negative information about [REDACTED] but rather, to explore your perceptions and experiences of person-centred care. Please keep in mind that as a researcher, I am required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that I may come across during the duration of the research.
8. Let me know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.
9. Are there any questions before we get started?

Introduction of Participants

Before we start, I'd like to know a little about each of you. Please tell me:

1. Your name
2. What your role is at [REDACTED]

Questions

1. What is your role at the organization and what are the responsibilities associated with that role?
2. How would you define person-centred care?
 - a. Probes: What does person-centred care mean to you? Who does it involve?
 - b. At meetings with staff or families, does this topic come up? If yes, what generally is discussed?
3. What considerations are important for person-centred care of older adults?
 - a. Probe: What components of person-centred care are important to you?
4. Are you aware of any policies in Ontario that discuss person-centred care?
 - a. If yes, which ones?
 - b. Do policies on person-centred care relate to receiving or delegating funding?
 - c. Do policies on person-centred care relate to accreditation by the Ministry of Health and Long-Term Care? Professional associations?
5. What do you think person-centred care looks like in practice in your organization?
 - a. Is it something you consider in assigning staff to certain residents?
 - b. How is it considered in developing residents' care plans? Life enhancement activities? Interpersonal interactions?
6. Has your organization made any changes to implement person-centred care policies?
 - a. If yes, what types of changes and in what areas? Did efforts involve collaboration with residents? Has there been any evaluation of these changes?
 - b. If no, why is that?
7. What are some things that happen in your organization that helps to implement person-centred care?
 - a. Family conferences? Nursing model of care? Variation of staff members?
8. What are some barriers to implementing person-centred care in your organization?
9. How do you think person-centred care can be evaluated in your organization?

Closing

Thank you for coming today and providing valuable input. Your comments have given us lots of different ways to see this issue. I thank you for your time.

Focus Group Script for Direct Care Providers

Introduction

Hello. My name is [name]. I'd like to start off by thanking each of you for taking time to participate today. We'll be here for about an hour.

The reason we're here today is to gather your perspective on person-centred long-term care at [REDACTED].

I'm going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

I also would like you to know this focus group will be audio-recorded. The identities of all participants will remain confidential.

Guidelines for the Focus Group (i.e. Ground Rules)

To allow our conversation to flow more freely, I'd like to go over some guidelines I would like all of us to follow which are:

1. Only one person speaks at a time. This is important as our goal is to make a written transcript of our conversation today.
2. Please avoid side conversations as this can be distracting.
3. Everyone does not have to answer every single question, but I'd like to hear from each of you today as the discussion progresses and so I may take time to make sure everyone has a chance to respond.
4. This is a confidential discussion in that I will not report your names or who said what to others. Names of participants will not be included in the final report that discusses the content of this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
5. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without worrying that your comments will be repeated later and possibly taken out of context.
6. There are no "wrong answers," just different opinions.
7. The purpose of this focus group is not to elicit negative information about [REDACTED] but rather, to explore your perceptions and experiences of person-centred care. Please keep in mind that as a researcher, I am required by law to report to the proper authorities any suspicions of neglect or abuse of long-term care residents that I may come across during the duration of the research.
8. Let me know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.
9. Are there any questions before we get started?

Introduction of Participants

Before we start, I'd like to know a little about each of you. Please tell me:

2. Your name
3. What your role is at [REDACTED]

Questions

1. How would you define person-centred care?
 - a. Probes: What does person-centred care mean to you? Who does it involve?
2. What considerations are important for person-centred care of older adults?
 - a. Probe: What components of person-centred care are important to you?
3. Are you aware of any policies in Ontario that discuss person-centred care?
 - a. If yes, which ones?
 - b. Do policies on person-centred care relate to receiving or delegating funding?
 - c. Do policies on person-centred care relate to accreditation by the Ministry of Health and Long-Term Care? Professional associations?
4. What do you think person-centred care looks like in practice in your organization?
 - a. Is it something you consider in assigning staff to certain residents?
 - b. How is it considered in developing residents' care plans? Life enhancement activities? Interpersonal interactions?
5. Has your organization made any changes to implement person-centred care policies?
 - a. If yes, what types of changes and in what areas? Did efforts involve collaboration with residents and family members? Has there been any evaluation efforts?
 - b. If no, why is that?
6. What are some things that happen in your organization that helps to implement person-centred care?
 - a. Family conferences? Nursing model of care? Variation of staff members?
7. What are some barriers to implementing person-centred care?
8. How do you think person-centred care can be evaluated in your organization?

Closing

Thank you for coming today and providing valuable input. Your comments have given us lots of different ways to see this issue. I thank you for your time

Appendix F

Demographic Forms



Is Long-Term Care Person-Centred? A Case Study

Demographic Form for Employees

Participant sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	Current employment title: _____
Number of years working in current role: _____	Number of years working within the area of senior care: _____
Number of years working within the area of healthcare: _____	Do you belong to a regulated healthcare professional body? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, which one? <input type="checkbox"/> Nurse <input type="checkbox"/> Physician <input type="checkbox"/> Psychologist <input type="checkbox"/> Social Worker <input type="checkbox"/> Other: _____
What is your employment type? <input type="checkbox"/> Full-time <input type="checkbox"/> Part-time <input type="checkbox"/> Casual	



Is Long-Term Care Person-Centred? A Case Study

Demographic Form for Family Members

Participant sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	Number of years as a council member: _____
Number of years with a family member living in long-term care: _____	



Is Long-Term Care Person-Centred? A Case Study

Demographic Form for Residents

Participant sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	Number of years as a council member: _____
Number of years living in long-term care: _____	

Appendix G

Final Set of Recommended Indicators for LTC by Dimensions of Health Care Quality

(Adapted from HQO, 2015)

Indicator	Timely	Patient-Centred	Safe	Effective	Efficient	Equitable*
Waiting for a place in a long-term care home						
Lost-time injuries on the job in long-term care						
Antipsychotic medication use among long-term care home residents without a diagnosis of psychosis						
Diminished physical functioning among long-term care home residents						
Improved physical functioning among long-term care home residents						
Worsened symptoms of depression among long-term care home residents						
Improved behavioural symptoms among long-term care home residents						
Potentially avoidable emergency department visits by long-term care home residents						
Pressure ulcers among long-term care home residents						
Pain among long-term care home residents						
Falls among long-term care home residents						
Use of daily physical restraints on long-term care home residents						

*Equitable is a cross-cutting domain – the assessment of equitable delivery should be incorporated into the measurement of all indicators where possible

Appendix H

Researcher Reflection

As a novel researcher, I began this research with openness and curiosity. I had the opportunity to visit Brookfield four times before conducting the focus groups. During those visits, I was given a tour of the facility, observed a monthly manager meeting and was able to introduce myself to the resident and family councils. Through these visits, I gained valuable insight into the operations of Brookfield from an external view. Conducting the focus groups exposed me to an internal perspective of care practices and the diversity of experiences across residents, family members and staff members. As a whole picture, what I observed in my experience at Brookfield was staff members and family members who are deeply committed to the well-being of residents. However, I also observed the inherent conflict of long-term care (LTC) as a workplace for some and a ‘home’ for others. Despite well-intended efforts, it was clear to me that LTC, as a workplace, continues to come first in the face of policy compliance and a culture of surveillance.

Listening to the perspectives of residents in this study, I heard and saw their lack of autonomy in areas neglected in conversations with other study participants such as the decision-making process to move into LTC in the first place or having access to leave their floor in the facility. In my opinion, LTC would ideally serve as a ‘home’ in the truest sense, whereby individuals living inside exist in the private sphere rather than the public sphere and are therefore allotted the autonomy that comes along with that. However, my knowledge and experience of the competing priorities and difficult decision-making that goes on in the LTC sector urges me not to advocate only for this idealistic transformation. Instead, my hope is that anyone who works or volunteers in LTC has the courage to acknowledge the humanness in every LTC resident and do

something about it to continuously act against the grain. Outside the walls of LTC, there must be additional advocacy for policy action that promotes a broader culture change movement; one that values human life into old age and throughout debilitating illness. Those closer to the beginning and middle of their lives must be engaged to support greater accountability across the life course for the aging population in recognition that all of us will someday need care.

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