Placing Person-Centred Care

By

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Abstract

While the recent adoption of a person-centred approach to long-term care in Canada has done much to address the shortcomings of its biomedical predecessors (particularly bringing to light the social-psychological aspects of living with dementia), it has not resulted in notable increases in quality of life for those who live in long-term care facilities. The aim of this dissertation is to contribute a relational and place-sensitive perspective of person-centred care that highlights where the approach could be better aligned with its experience and ultimately informs a higher quality of life for people living in long-term care environments. To do so, empirically expressed tensions in the lived experiences of long-term care facilities espousing person-centred care are considered through the lens of a relational landscapes of long-term care framework derived from the burgeoning field of geographical gerontology. A qualitative, community-based, multi-site case study methodological design guided the collection of interviews with residents, staff and family members in three long-term care facilities designed to elicit their lived experiences. Observation periods in each facility contributed to my own perspective of the care environments. Tensions expressed within each of the empirically emergent themes that shaped the lived experiences of participants (atmosphere, flexibility and relationship-building) were considered as they relate to the core concepts of home(place), care and personhood to expand person-centered care and contribute to (while simultaneously arising through) the landscapes of long-term care framework. Specifically, the expansion of conceptions of home as a functional, familiar potential beyond its locational aspects; of care to incorporate a broader range of relationships and the potential of the built environment to foster these relationships; and of personhood as a de-centered process rather than a uni-directional outcome were found to be the potential nucleus of an expansion of person-centred care that addresses its experiential and conceptual tensions. Conceptually, the contribution of this research is an advancement of relational understandings of place and care in the long-term care context.
# Table of Contents

**Abstract**

List of Tables .......................................................................................................................... vi

List of Figures .......................................................................................................................... vii

Chapter 1 Introduction ............................................................................................................. 1

1.1 Wherever you go, there you are: Locating myself in the research ........................................ 3

1.2 Long-term care context in Ontario, Canada ........................................................................ 4

1.3 Critical perspectives on long-term care in Canada: Framing the adoption and implementation of person-centred approaches .................................................................................. 6

1.3.1 Conceptualizing care ..................................................................................................... 7

1.4 Dementia care and person-centred care: An internal critique ............................................ 15

1.4.1 Original contributions to dementia care studies .............................................................. 17

1.5 Geographical gerontology: Constructing a landscape of LTC beyond PCC ......................... 18

1.5.1 Original contributions to geographical gerontology ....................................................... 19

1.6 Qualitative methodology and theoretical orientation ......................................................... 20

1.6.1 Theoretical orientation ................................................................................................. 20

1.6.2 Methodological design and methods ............................................................................ 21

1.6.3 Content analysis .......................................................................................................... 21

1.7 Dissertation structure and layout ....................................................................................... 22

Chapter 2 Framing the critique: Person-centred care in the dementia care literature ............... 24

2.1 The standard paradigm ..................................................................................................... 24

2.2 Locating person-centred care .......................................................................................... 26

2.3 Person-centred care and its internal tensions ................................................................... 28

2.3.1 Kitwood’s critique of the standard paradigm and the dialectic of dementia ................... 29

2.3.2 Ill-being, well-being in dementia ................................................................................ 31

2.3.3 Personhood: The key source of tension in person-centred care ................................... 33

2.4 Conceptual contributions to dementia studies ................................................................... 40

Chapter 3 Framing a landscape of long-term care: Geographical gerontology and experiences of person-centred care .......................................................................................... 43

3.1 Geographical gerontology ............................................................................................... 43

3.2 Relational conceptions of place ....................................................................................... 46

3.3 Landscapes of (long-term) care ........................................................................................ 47

3.3.1 Surrounding policy perspective – Ageing in place and home ....................................... 49

3.3.2 Home and home care .................................................................................................. 51

3.3 Relational properties of home: Framing a landscape of LTC ............................................. 55

3.4 Conceptual contributions to geographical gerontology .................................................... 61

Chapter 4 Research design and methods ............................................................................... 63

4.1 Theoretical orientation .................................................................................................... 63

4.1.1 Ontological orientation: the locality of being .............................................................. 64
Chapter 7 Relational place and long-term care: Concluding thoughts and reflections .......................... 158

7.1 Conceptual advancements ............................................................................................................. 158
  7.1.1 Care, personhood and place (home) reconsidered ................................................................. 159
  7.1.2 An emergent ‘landscape of LTC’ ......................................................................................... 163

7.2 Methodological contributions ......................................................................................................... 164

7.3 Practical/community-based contributions ....................................................................................... 165

7.4 Long-term care policy implications ............................................................................................... 166
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.5 Limitations and suggestions for future research</td>
<td>167</td>
</tr>
<tr>
<td>7.6 Original contributions</td>
<td>170</td>
</tr>
<tr>
<td>7.7 Personal reflections: PCC reconsidered</td>
<td>171</td>
</tr>
<tr>
<td>Bibliography</td>
<td>173</td>
</tr>
<tr>
<td>Appendix I General Research Ethics Board Approval</td>
<td>187</td>
</tr>
<tr>
<td>Appendix II Letter of Information / Consent for Family, Staff and Management</td>
<td>189</td>
</tr>
<tr>
<td>Appendix III Consent/Assent for Residents</td>
<td>183</td>
</tr>
<tr>
<td>Appendix IV Interview Guides for Family, Staff and Residents</td>
<td>185</td>
</tr>
<tr>
<td>Appendix V Recruitment Poster</td>
<td>187</td>
</tr>
</tbody>
</table>
List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 The Relational Conception of Place in Geographical Gerontology</td>
<td>47</td>
</tr>
<tr>
<td>4.1 SE LHIN LTC Characteristics Compared to LTC in Ontario</td>
<td>72</td>
</tr>
<tr>
<td>4.2 Summary of Facility Characteristics</td>
<td>78</td>
</tr>
</tbody>
</table>
## List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Scope of Geographical Gerontology</td>
<td>45</td>
</tr>
<tr>
<td>4.1 The Geography of the Southeast LHIN</td>
<td>72</td>
</tr>
<tr>
<td>4.2 F2’s Philosophy of Care Tenets</td>
<td>77</td>
</tr>
</tbody>
</table>
Chapter 1 Introduction

Canada’s population is rapidly aging. In 2011, the first wave of the baby boomer generation turned 65. While dementia is not a normal part of the ageing process, the risk for developing a form of dementia doubles every five years after the age of 65 (WHO, 2012). In Canada, approximately 747,000 people were living with dementia in 2011, 15 percent of those aged 65 and older. The Alzheimer Society of Canada also tell us that by 2031, if nothing changes in Canada, this figure will increase to 1.4 million (Alzheimer Society, 2012). Additionally, an expansive adoption of the social policy of aging in place, an approach borne out of geographical thinking, has led to people living with dementia staying in their home for as long as possible until the progression of the disease results in increasingly complex care needs and the greater likelihood of institutionalized care (Eska et al., 2013). Indeed, the proportions of individuals with dementia in institutional care settings is large in Canada and is growing as people are both living longer and being encouraged to stay in their home for as long as possible.

Lexchin (2013) notes that dementia is the leading disorder within long-term care (LTC). Lexchin’s report provides some glaring statistics showing that although the proportion of elderly Canadians who live in LTC settings has declined since 1981, in 2006 it was still 1.4% of those aged 65-74 and 12% of those 75 and over for a total of just under 275,000. Sixty percent of those living in LTC had severe cognitive impairment compared to fourteen percent of older adults living in the community (Lexchin, 2013). This substantial demographic shift places dementia as an important social and health issue that needs to be confronted by Canadians as the population continues to age. What is equally important is the lack of study of the approaches geared towards people living with dementia in LTC facilities.

Although this statistical portrait is helpful in that it brings much-needed political and popular attention to the issue, the more complex and equally important problem is the social nature of the disease. Older adults are marginalized in society based on ageist attitudes and those living with dementia are affected on an even deeper level due to the cognitive nature of the
disease (Brooker, 2004; Hughes, 2013). This amounts to a lack of voice in their own representation based on negative and often false, perceptions of what it means to live with dementia. In response to these increasingly complex care needs for residents in LTC and the shortcomings of the biomedical model for understanding and caring for people in LTC, many facilities have adopted a care model/approach based on person-centred care (PCC), a philosophy and approach borne out of dementia care theory. While the adoption of PCC has directed attention to the social-psychological aspects of identity, health and care, there remains a disconnect between theory and the outcomes in practice. That is, its implementation has not resulted in a meaningful increase in the quality of life in LTC facilities in Canada, pointing to potentially problematic aspects in both the context for its implementation as well as the approach itself.

The aim of this dissertation is to contribute to a conceptual expansion or continuation of the project of PCC towards an approach to LTC that is better aligned with the quality of life or lived experience it aims to support. Further, the broad conceptual goal is to align the disciplines of critical gerontology and geographical gerontology that share a concern for and interest in the quality of life for older adults in LTC and those living with dementia. This is accomplished by highlighting their shared espousal of relationality as a conceptual bridge and way forward beyond static and one-directional approaches to the core concepts of care, personhood/identity, and home/place.

To realize this expansive conceptual goal, the critiques of PCC as depicted in critical gerontological literature are considered alongside their empirically-founded experiential manifestations through a spatially sensitive and relational lens rooted in geographical gerontology. This analysis ultimately contributes to the construction of a novel ‘landscape of LTC’ framework in geographical gerontology and a subsequent expansion of the previously mentioned concepts at the heart of PCC and thus, an expanded perspective of PCC itself that reflects both its current experiential tensions alongside its core conceptual critiques. This broad
multi-disciplinary goal is built upon a number of specific objectives that guide the methodological, practical/community-based and conceptual approaches, each leading to distinct but aligned contributions:

- **Conceptual** – To consider empirically gathered experiential tensions in LTC environments informed by PCC in light of its conceptual critiques from salient bodies of literature. This is done by engaging with a relational framework for understanding the person/place transactions developed from scholars in geographical gerontology. Specifically, the core concepts of care, personhood and home are reimagined as dynamic, and processual aspects of the LTC experience in an effort to expand PCC from within. This contributes to a conceptual de-centering of the LTC approach that might help to inform a better alignment between approaches to care and quality of life for the people involved.

- **Practical/Community-based** – To work with participating LTC facilities to develop, carry out and disseminate the project in a way that supports their internal goals and those of the community at large. This community-based approach ensures that the research is done with rather than for participating facilities in a symbiotic partnership. Additionally, a dissemination of the results back to participating facilities provides them with valuable perspectives to inform ways to better meet the needs of all of the groups involved.

- **Methodological** – To collect empirical qualitative data from staff, family and residents in three LTC facilities espousing PCC-based approaches and elucidate the lived experience of such facilities. A further focus is on the tensions portrayed in their experiences as these represent the gaps or points of possible expansion in PCC to be discussed in terms of the conceptual critiques and consequential ways forward. Further, within this general methodological objective is an opportunity to create a discursive space to hear the voices of residents, particularly those living with dementia, and their own representation of the experience of PCC.

1.1 Wherever you go, there you are: Locating myself in the research

Before providing the specific research context, this reflexive section locates me in this research expressing my motivation for studying this topic as well as making explicit the perspective through which this research came about and was undertaken. An acknowledgment and celebration of the blurring of researcher and researched underlies this discussion where the scholarship is inextricably linked to and influenced by the particular perspective of the researcher (Fenton and Baxter, 2016). On a professional level, this project is a continuation of my Master’s (MA) research titled, *A Case Study Exploring the Implementation and Lived Experience of Person-Centred Dementia Care at The Lodge at Broadmead* (Plumb, 2014), where I applied a similar qualitative approach to understanding an implementation of PCC. That project was
descriptive in nature, seeking to understand why and how LTC facilities were taking up PCC approaches as alternatives to past medical and clinical-based approaches. While my PhD project is more evaluative and goes much further to understand the benefits and pitfalls of such approaches, the MA experience provided a strong base of understanding how to do research with all those people involved in LTC, the nature of PCC approaches, and the importance of continuing to contribute to a higher quality of life for people living in LTC particularly those living with a dementia. Many hours of volunteer work in the participating LTC facility for my MA research led to a great appreciation and admiration for those residents living with dementia who I developed lasting relationships with through my role to simply spend time with them where staff was not available. Along with the close relationships I have held with the older adults in my own personal life, it is these relationships that ultimately inform my ongoing drive to challenge society-wide attitudes and beliefs about older adults in an effort to improve their quality of life.

1.2 Long-term care context in Ontario, Canada

The general role of LTC is: to offer 24 hour nursing care and supervision; primary medical care; help with activities of daily living and interests; and a safe, caring home-like environment. Ontario’s LTC facilities provide care and support to more than 115,000 people and their families every year. LTC facilities in Ontario are licensed and funded by the Ministry of Health and Long-Term Care, while residents also pay a fee for their accommodation. Further, the provincial government provides funding for all the staff and supplies related to nursing and personal care, resident social and recreational programs and support services, and raw food while residents pay an accommodation fee to the LTC facility that is used to pay for expenses such as non-care staff, utilities, and mortgages, as well as building maintenance and major capital repairs (Ontario Long-Term Care Association, 2019). Individual LTC home operators are granted a license to operate by the provincial government with the expectations that they follow the requirements of the Long-Term Care Homes Act (LTCHA), one of the most rigorous pieces of LTC legislation in the world.
Due to a recent provincial focus on aging at home along with stricter standards for admission to LTC, people are now entering LTC with more complex care needs than ever. In fact, the vast majority of people living in LTC in Ontario have some form of cognitive impairment (90%) while 64% of residents are living with a diagnosis of dementia (Canadian Institute for Health Information, 2018). These statistics show Ontario’s LTC facilities as the province with the highest prevalence of these conditions in Canada. This changing face of LTC and how it has led to the uptake of PCC is reflected in the LTCHA’s first line stating, “The people of Ontario and their Government: Believe in resident-centred care” (Government of Ontario, 2007, pg i).

While individual LTC facilities are free to develop their own mission statements that makes clear the principles, purpose and philosophy of care of the home, they are required to align such mission statements with the overarching goal of resident-centred care (a semantic rebranding of PCC), the “Fundamental Principle” stated in the LTCHA which fleshes out resident-centred care, and the extensive Resident Bill of Rights again stated in the LTCHA. Such stringent provincial guidelines coupled with the knowledge that over the next 20 years it is anticipated that there will be more than twice as many seniors over the age of 75 and, by extension, a growth in the number who need long-term care support places an immense burden on staff in LTC to account for both the complex care needs of residents and the rapidly rising number of residents (Ontario Long-Term Care Association, 2019).

Indeed, a recent 2019 report from the Ontario Long Term Care Association (OLTCA) urges the Ontario Government to provide LTC facilities with a higher level of funding for more frontline staff, a higher level of flexibility to use government funding to hire different types of support staff than is currently allowed in the LTCHA and ultimately to work with LTC facilities to create a provincial funding strategy that addresses staffing shortages and allows for more facility-based creativity to meet resident needs. While the provincial emphasis on resident (or person) centred care does well to focus attention on the dignity and needs of residents, recent
critical perspectives have shone a light on its structural and internal limitations that align with OLTCA’s policy-based suggestions.

1.3 Critical perspectives on long-term care in Canada: Framing the adoption and implementation of person-centred approaches

According to a staff member in one of the LTC facilities participating in this project, “Long-Term Care in Canada is over regulated, over scrutinized and under resourced.” This was not an uncommon realization for staff members working in all three facilities, a realization that begs the question of how we got here conceptually, politically and practically and perhaps more importantly, how can we improve our understanding and implementation of care to allow caregivers to succeed as a result of, rather than in spite of the context? This section will explore a wide range of care literature to provide an in-depth and critical discussion about how care is understood, organized and practiced in Canada. It identifies the key tensions and contradictions in the current prevailing approaches (such as PCC) along with promising alternative orientations found in the literature. Although this review spans perspectives from scholars in the social sciences, health sciences, disability theory, gerontology, policy analysis, philosophy, cultural studies and others, questions about care have largely been taken up by feminist researchers and specifically from a feminist political economy approach (Armstrong and Armstrong, 2004; Armstrong & Braedley, 2013; Folbre, 2008).

Given the current realities of the care context in Canada for woman in particular, it is not surprising that the discussion of care has been taken up by feminist researchers. It is clear that the vast majority of both formal and informal care in Canada is provided by women (Armstrong and Braedley, 2013). Further, women face inequitable treatment stemming from an expectation to provide care in the household and community coupled with a lack of supports for such care work and a segregated labour force. Women’s health and economic security is thus threatened by the nature of their involvement in this unpaid labour to a far greater extent than their male counterparts (Armstrong and Braedley, 2013; Pederson and Huggan, 2001). The political and
economic context of care arrangements are thus critical factors for women’s opportunities to engage in meaningfully and equitably compensated paid work.

Care through a political economy lens is considered with respect to how it is structured and lived experience is influenced by and influences political, economic, historical and social relations. A feminist political economy lens extends this focus to emphasize interactions between market and domestic relations including the question of how to account for the sexual division of labour amongst human activity (Armstrong and Armstrong, 2003; Bhattacharyya 2009; Vosko, 2002). A recognition that care is not done in a vacuum but rather in and of its social, political and economic context and that it is predominantly a form of work (paid and unpaid) undertaken by women makes this approach particularly apt for analyzing the situation. Viewing care in Canada through this lens leads to a number of tensions that underlay care policies that need to be attended to if equitable care strategies are to be developed (Armstrong, 2012). Asserting that care is a basic human right, Armstrong (2012) refers to tensions underlying unpaid/informal care; those between obligation and affection; tension between the rights of the person requiring care and those of the person doing the care; decision making around what care is needed and how it is provided; and tensions about who is responsible for care. Additionally, Glendinning (2008) notes the potential for tensions that may arise from espousing social care policies that emphasize notions of independence and individual choice such as PCC. The following section will explore these tensions through a critical outline of how care is conceptualized in Canada as well as the emergence and critiques of person-centred approaches.

1.3.1 Conceptualizing care

Inquiring into how care is conceptualized allows us to think critically about its more specific tensions that arise. Prevailing conceptions of care may fail to capture/consider important aspects of people’s experiences, especially if developed on the foundation of dichotomies that simplify the diverse actors and complex realities of care in practice (Daly and Lewis, 2000; Day, 2013; Henderson and Forbat, 2002). Additionally, discussing PCC in the context of the LTC
literature will help to contextualize the approaches’ internal tensions elaborated on in Chapter Two as well as those expressed empirically regarding its lived experience in later chapters.

The review begins with a critical analysis of how care is imagined in Canada based on an engagement with the dynamic social, political and economic landscape in which care is situated to “contextualize models of care within the broader relationships that both inform their definition and shape their experiences” (Day, 2013, p. 21). Day provides us with a framework for the foundations of care as it has been conceptualized in four key areas: social policy, by health professions, by care organizations, and in care interactions.

*Social Policy – The Family Model of Care*

Day (2013) notes that within care literature, the implicit propensity of Western countries to support a “family model” of care in their social policy has been a critical focus. The central premise as well as the fundamental critique of this model is its assertion of care as an individual concern which acts to legitimize its firm location in the private domain (Graham, 1991). Two unified sets of assumptions arise within care policy based on this assertion: first, policies that define care as a private, individual responsibility tend to romanticize care in the home as that linked with feelings of love and security while positioning the home as the best possible place to provide/receive care (Armstrong and Braedley, 2013; Dalley, 1996); second, such a policy focus on care in the home tends to be represented within an ongoing narrative of care “crisis,” including the insistence on the need to cut back on care costs and that families are required to step in as a result (Aronson and Neysmith, 1997; Milligan, 2009). The former is often framed as a ‘private informalization’ of care where the responsibility lies more and more in the hands of unpaid and informal caregivers in their homes becoming less visible and less subject to contestation and opposition while the latter is often referred to as an ‘informal privatization’ in recognition that most home care is provided on an unpaid basis by friends and/or family members who may be doing so by necessity rather than by choice (Andrews and Phillips, 2005; Milligan, 2009; Wiles 2005).
The consequences of these trends are not equitably distributed across the population due to the gendered division of labour in the home and the association of caring with “women’s work” which amount to woman taking on the majority of the costs and responsibilities (Leira and Saraceno, 2002; Wiles, 2005). Moreover, in falling outside of the family model of care’s private and individualized focus, institutionalized care has largely been demonized as a less desirable or inappropriate outcome (Dalley, 1996).

Many authors also note that the tendency within the family model of care in social policy to offer exclusionary and binary conceptions of the relationship between carer and cared for has resulted in policy that develops supports for one or the other roles (Aronson and Neysmith, 1997; Daly and Lewis, 2000; Fine, 2004). Henderson and Forbat (2002) describe the resulting reification of static identities for each role as a one-way trajectory of care delivery where the carers are marked by independence and the cared for by dependency on carers. This assumed independence is said to undermine the needs of carers while, as (Havinsky, 2004) notes denies the universal need for care, as dependency (within a model that promotes individual personal responsibility for care) is viewed as an abnormal condition.

The main thrust of feminist political economy critiques of the family model of care in a social policy context is an urgency to think about care in ways that reflect on the link between private experiences of care and the public organization of care supports. The family model is said to propagate a false dichotomy between the public (social)/private (individual) aspects of care leading to disconnects between social care provisions and individual care experiences. Moreover, Campbell (2013) notes that restructuring and reform of health care policy in Canada based on the family model and a gradual shift to a “lean and neoliberal state approach has resulted in an essential transfer of the burden of risks and responsibilities for health and health care from the state to families, individuals and the market” (pg. 89). I will consider later in this chapter how this individual, family and market focus may be reflected in the proliferation of approaches such as
PCC and the ability (or lack thereof) for facilities to actually provide an experience of care that lives up to PCC’s promises.

*Health Care Systems: The Medical Model of Care*

Similar to the family model, a current emphasis on the medical model in the health care system has been critiqued for defining care needs and tasks in a narrow and one-dimensional way resulting in an individualized and purely physical/bodily notion of the responsibility for care (Armstrong and Armstrong, 1996; Raphael, 2000). In this case, care needs are defined biomedically where, “health becomes synonymous with ‘cured’ and care becomes an intervention towards that end” (Day, 2013, p. 25). Health problems are only located in the body while environmental and social impacts on health are disregarded (Raphael, 2000). Bodies are the objects of care and are to be monitored by experts in the medical professions while care itself adopts the role of bodily regulation, oversight and treatment (Cancian, 2000; Day, 2013; Twigg, 2002).

Although this model has been largely critiqued in the nursing literature in favour of an emphasis on psychological and emotional aspects of care, Keighly (2006) notes that this emotional approach itself has been critiqued for going too far and ignoring the physical aspects of care work as well as the body of the care recipient. In fact, within the medical model of care there exists two distinct but related approaches: the dominant biomedical approach and a strictly psychological and emotional approach to care. Both of these approaches rely on an essential mind/body division in how we understand care, each relegating the other as a lesser care consideration. While the biomedical approach acts to dehumanize people receiving care, the purely emotional/social approach justifies a delegation of the hands-on, physical work of care to poorly paid workers who are not afforded any level of professionalized status (Day, 2013; Weinberg, 2006). For example, Weinberg (2006) critiques the material/emotional dichotomy in care by showing how physical nursing tasks are often made possible (or meaningful) only through forming emotional connections with patients. She argues that expressing and fostering emotional...
connections is a skill in itself that has dire implications for the embodied experiences of carers and cared-for and in doing so illustrates that an essential separation of these aspects of care overlooks many of the nuances of the care experience. Researchers have suggested that we ought to move beyond these one-dimensional models through analyses of how wider structural contexts affect the experience(s) of care (Day, 2013; Twigg, 2000; Weinberg, 2006).

The Market Model of Care Work Organizations

In Canada, regardless of whether LTC facilities are publicly funded or run privately ‘for-profit’, there has been a gradual general increase in the use of market principles for the organization of care (Daly and Lewis, 2000; Day, 2013; Fuller, 1998). Within the market model, care tasks and needs are thinly conceptualized as only those which can be measured and quantified. Care tasks are then allocated market-based value as a suite of services provided for the cared-for as clients (Knijn, 2000). In the context of long-term care, where care work is romanticized as being intrinsically fulfilling and based on loving, family-like relationships, the application of market principles is particularly problematic. Indeed, Day (2013) aptly describes the logical disconnect that underlies this context: “the task-based, results-focused organization of care in the market model precludes the possibility for a concept of care beyond tasks that can be quantified, while at the same time this model is sustained by the association of care with the ideals of altruism and self-sacrifice” (pg. 27). In this discursive context, care workers are often compelled to perform tasks for which they are unpaid as they do not fall within the narrowly defined range of paid duties as defined by market model considerations due to a perceived obligation to fulfil an altruistic care ideal (Baines, 2004). To move beyond the market of care model, it is necessary to critique the quality of care and the market-model’s arbitrarily (or financially) justified care needs in a way that transcends any appeal to romanticized forms of caring. We will see later in this chapter how PCC and other progressive approaches can lead to only superficial or semantic improvements and this is due at least in part to interactions with the market model in their implementation.
On an interpersonal level, care has been taken up broadly through the social model as a relational process where such relationships are said to be developed exclusively through the efforts of the carer onto an inert cared-for individual (Day, 2013; Hochschild, 1995). In this model, relationality is a one-way process whereby, “care is positioned as the effect or outcome of only one social actor, the carer, while the cared for are relegated to the role of passive objects of emotional caring labour” (Day, 2013, pg. 28). The main theoretical critique of this position is that it is uni-directional in that it ignores the ways that the cared for may be undertaking such emotional care labour and subsequently the ways that carers themselves may require such care (Henderson and Forbat, 2002). Indeed, while this model can help to justify tending to the social and psychological needs of residents, it implicitly precludes the carer’s needs as well as possible contributions from the residents themselves in institutional settings. Nevertheless, the adoption of PCC along with its diverse characterizations such as resident-centred or patient-centred as expectations built into residential care policy in Ontario can be viewed as at least partially an extension of the uptake of this social model.

Marked as something approaching a panacea for all issues affecting care provision (e.g., dehumanization of care recipients, over-medicalization of care provision, and the shortcomings of one-size-fits-all care), PCC has become a common designation in Ontario LTC policy documents and the academic literature (Alzheimer Society of Canada, 2013; Munthe, Sanderman and Cutas, 2012; Smele and Seeley, 2013). While an in depth description of PCC and its internal critiques is provided in Chapter Two, the approach (as understood through the lens of the previously discussed, pervasive models for conceptualizing LTC) has been critiqued in critical gerontology for overvaluing resident autonomy/will and independence at the expense of conceptualizations placing care in interdependent and relational networks (Nolan et al., 2004). In the broader context of “governments preoccupied with both limiting public provision of needs and facilitating the expansion of private- sector methods and delivery across care sectors,” it is no surprise that
values of independence and self-determination pulled out of PCC have been taken up with such vigour (Smele and Seeley, 2013, pg. 145). As noted earlier, such values are irreconcilable with the notion that care is a shared societal responsibility and their emphasis puts much pressure on individuals and family members when it comes to care responsibilities. Within this context there is a weak relationship between models of care promoting individual choices and care delivery (Zimmerman et al., 1997). Insights from feminist political economists strive to move towards a version of PCC that rather emphasizes interdependence, context and relationships which are more compatible with public care provisions (Armstrong and Braedley, 2013; Daly, 2013).

More specifically, Armstrong (2012 and with Braedley, 2013) exposes some of the tensions in the practice of PCC in residential care facilities in Canada, finding that three key tensions arose from participant descriptions between: obligation and affection (for family members); decision making based on individual versus collective needs (for residents); and the needs and requirements of providers and residents. She notes that while the espousal of PCC in the LTC sector may be a positive development towards meeting resident needs, these tensions cannot be resolved by PCC as it is currently conceptualized. Further, if these tensions are not sufficiently attended to through an expansion of the approach it is possible that PCC (or resident/patient-centred) is no more, “than a political slogan to identify a user-based approach to care.” (Edvarsson et al., 2010, pg. 2612) Armstrong also notes that it is imperative to locate and explore other tensions in this context and to address these tensions using diverse strategies and approaches. Daly (2013) echoes this need for a society-wide ontological move beyond tenets of PCC noting, “it is necessary to move from simply thinking about the person at the centre of care to a model that is supported by a relational ethos of care that is instilled at all levels of our society” (pg. 45). She advocates for a relational, interdependent and ‘multi-scalar’ communal ethos of care incorporating a wider range of analysis (as opposed to solely focusing on the ‘micro’ level) to replace or expand the current individual ethic of care.
This body of gerontological literature generally provides the structural critique of the conditions within which PCC has emerged and been implemented, and the failure of PCC to extend beyond such structural elements. An individual-focused, unidirectional, market-based conceptualization of care has led to conditions under which approaches such as PCC are applied merely as inert political slogans for a user-based care approach that acts to gloss over the underlying issues around care (Edvarsson et al., 2010). Thus, rather than a meaningful tool for positive and fundamental change, PCC and its ilk (resident-centred, patient-centred) have been coopted to reinforce or provide a smoke-screen for pervasive structural inequities (Armstrong and Braedley, 2013).

The resulting call from the critical literature on LTC that this dissertation addresses is to continue to critically assess PCC-based approaches through a diversity of perspectives and styles in an effort to justify and inform an expansion of how we ought to conceptualize care in general (i.e., what is it, whose responsibility is it, how is it done). The main contribution of this dissertation reflects the re-animation of care through an exploration of its tensions in practice in light of the conceptual critiques by viewing them through a theoretical lens borne out of a relational conception of place in geographical gerontology. In other words, this project provides a new perspective of care as it is experienced in particular places viewed as relational entities, by showing the current tensions in practice as manifestations of conceptual critiques which justifies the ongoing project of expanding the concept.

Additionally, critical gerontology scholars specifically call for a reimagining of care as a relational and dynamic concept as a remedy for the one-way and individualized notion espoused in current care approaches including PCC (Day, 2013). This focus on relationality is a key theme running through the dissertation as it functions as both a conceptual vector for expansion of core concepts and a common conceptual pathway to bridge the core disciplines.
1.4 Dementia care and person-centred care: An internal critique

Increasing disfavour towards the traditional paradigm of clinical and social care of people living with dementia along with the recognition of a shifting demographic in LTC that has resulted in a vast majority of residents living with a form of dementia has led to an uptake of PCC as a guiding approach for LTC. As this approach was borne out of the dementia care literature, this body of work provides a rich understanding of the theoretical and practical underpinnings of PCC and the internal conceptual tensions that help frame the discussion for the research undertaken in this dissertation. The review of dementia care is largely built from seminal works such as Baldwin and Capstick, 2007; Innes, 2012; Innes, Kelly and McCabe, 2012; Kontos 2005 and Kitwood’s initial formulation (largely summed up in his penultimate 1997 contribution) which was explicitly an unfinished project but problematically remains largely intact in current applications. This recognition alone provides context for a conceptual expansion of the approach; however, the body of literature in dementia care provides more specific internal gaps to be addressed for a more pointed analysis.

The person-centred approach to dementia and dementia care, developed by the late Tom Kitwood considers the experience of a dementia as a dialectic between physical/neurological and social-psychological features. The goal of dementia care then, is (re)frame as maintaining and enhancing personhood which is famously defined as, “a standing or status that is bestowed upon one human being by others, in the context of relationship and social being” (Kitwood, 1997, pg. 8). Kitwood justifies this requirement of acknowledging the person through a moral solidarity or recognition of the essential unity of human beings regardless of their differing abilities. He bases the social imperative on Martin Buber’s premise of the primacy of relationships as the building blocks of the self, encapsulated in his famous saying, “All real living is meeting” (Buber, 1937, Pg.11). PCC counteracts the biomedical, standard paradigm for understanding the experience of dementia through an amplification of the social and psychological supports that are based in
social relationships and the continuing personhood or human-status of the person living with dementia.

As a philosophy, PCC underlies a broad cultural shift in how we think about and how we do dementia care (Puurveen and Drance, 2012). This shift can be viewed as a continuum where the move towards PCC does not completely replace the former approach (biomedical/standard paradigm) but rather expands it to better align with novel understandings of the situation/experience. To contribute to a further progression along the culture shift continuum this dissertation agitates PCC in terms of its practical, conceptual, and methodological shortcomings showing a new understanding of it.

In a practical sense, PCC has, at least in name, been viewed as a panacea to all of the core issues surrounding dementia and dementia care since its adoption into dementia care policy (Packer, 2003). Presently synonymous with good care, this orthodoxy creates a situation where most of what passes for PCC is an empty label that facilities must have to acquire funding and satisfy policy requirements. Rather than a flexible and ethical care approach, it has largely been demoted to an innocuous and static label in practice (Nolan et al., 2004; Hughes, 2008). Indeed, although PCC is often championed in institutions’ mission and philosophy statements, tensions exist when implementing the philosophy into professional practice at institutions in a way that has a real effect on the quality of life for residents, staff and families (Hebblewaiathe, 2013).

PCC has been further internally critiqued on a conceptual level in ways that help make sense of, and can be expanded through, consideration of experiential tensions that were found empirically through the research in this dissertation (Chapters Five and Six). Specifically, this project responds to calls in the dementia care literature to reimagine PCC’s core tenet of ‘personhood’ as a dynamic, relational process that is intimately intertwined with the concept of home and place in general (Baldwin and Capstick, 2007; Downs, 2013; Martin et al., 2013). Notably, in glossing over the relational aspects of personhood and home, the concepts have become vulnerable to precisely the reductionist, categorical biomedical criteria that PCC initially
sought to move away from (Kontos, 2005). In this sense, there is a disconnect between creating a static home-like environment solely in the physical sense and a home-like processual experience which is linked to phenomena beyond a generic material construction of a place that simply looks like a home. These critiques provide conceptual context for the empirical experiential findings (Chapters Five and Six) while the project contributes to the literature by further situating them as experienced tensions in practice.

Methodologically, there has been limited research done regarding the lived experience of PCC from the perspective of people living with dementia (McCormack and McCance, 2010; Epp, 2003; Edvarsson et al., 2008). This is mainly due to difficulties in consent and understanding that tend to accompany this type of research.

In addition to these critiques that focus specifically on PCC, there has been a general call for a greater engagement in theory in dementia care as Pia Kontos (2005) tells us, “While care practice is providing evidence that challenges the negative and deterministic view of the standard paradigm, until and unless this subsidiary discourse is embedded in a clear theoretical framework, the standard discourse will prevail.” (p.564). Similarly, theory is needed to provide a wider lens through which to view behavior to expand on disease pathology and/or individual micro-level contexts (Innes, 2012; Kontos, 2005). The core value of the research in this dissertation with respect to this body of literature, then, is to continue to extend the project of PCC through conceptual and experiential points of interest in the same way that others extended approaches beyond a biomedical framework based on what was lacking. A novel framework is required to breathe new life into a concept that has become stagnant and no longer (if it ever did) aligns with its lived experience.

1.4.1 **Original contributions to dementia care studies**

Beyond advancing the ideas of relational care, the dissertation contributes to dementia care studies by highlighting the ways that place affects LTC experiences to add new sensitivities to relation-centred care. Specifically, the dissertation shows the potential for resident to resident
relationships and how these can be fostered through consideration of the built environment. Such a sensitivity to aspects of place viewed relationally provides a perspective beyond the extensive existing discussion of the social-psychological environment and inclusion of family members found in the dementia care literature.

1.5 Geographical gerontology: Constructing a landscape of LTC beyond PCC

As a bourgeoning branch of health and human geography, geographical gerontology is a discipline that employs a multi-disciplinary bent to the question of how where we are affects how we are, and how that relationship changes as we age (Andrews et al., 2009; Skinner et al., 2018). An emphasis on the core concepts of place, health and identity situates geographical gerontology as one that has much potential as a basis for expanding on the previously highlighted concepts from the LTC and dementia care literature. For this project, works in this field provide a conceptual pathway to understanding PCC through a relational place-based understanding of its experiential tensions. A relational and dynamic conceptualization of place as provided by, among others, (Darling, 2009; Jones, 2009; Wiles, 2005), drives this specific inquiry and bridges the core disciplines through a shared engagement with relationality as a conceptual way forward.

While the geographies of home care and community care for older adults have been developed extensively, the relationship between older adults (and other salient groups) and the LTC facilities in which they live, has received little attention in the literature. The lack of research about this important group and LTC is ultimately shown in its lack of attention in the recent overview of topics covered in the field by Skinner et al. (2018).

These new voices will inform and contribute to the construction of a ‘landscape of LTC’ framework which follows Milligan’s (2010) sizeable conceptual footsteps in her development of the ‘landscapes of care’ framework. A framework built upon a relational conception of place is employed to understand and expand the conceptual critiques manifest as experiential tensions in a place-sensitive manner. Borrowing from an existing lens developed from interrogations of the experience of care at home, the landscapes of LTC framework considers relational (Cloutier et
al., 2015; Martin-Matthews and Cloutier, 2018) aspects of place to highlight the forces that
impact an experience of LTC while allowing for the uptake of emerging experiential themes to
further develop from within. That is, the landscape of LTC lens both structures and is shaped by
lived experiences as they emerge as a processual enterprise.

In sum, substantive conceptual critiques of PCC developed in the critical gerontological
literature are engaged with through a novel ‘landscape of LTC’ framework to provide a new
voice to geographical gerontology while simultaneously showing new understandings of the
existing conceptual critiques. While literature in critical gerontology provide language to discuss
the tensions discovered in practice, it is geographical gerontology that provides a conceptual
means to move forward and these two purposes are symbiotic in that they amount to a
contribution in each salient discipline.

Bringing distinct bodies of literature together in this way to erode disciplinary silos
provides each with the ability to more seamlessly borrow concepts and findings as, while the
nomenclature and particular focus differs slightly, they all have engaged with similar broad
philosophical movements in the social sciences (relational turn) and they all seek to ultimately
make life better for persons living with dementia.

1.5.1 Original contributions to geographical gerontology

In geographical gerontology LTC is a context that is relatively unexplored and the
contribution this dissertation makes to this scholarship is to draw directly from these unexplored
experiences of the staff, family and residents in a LTC facility to add to our understanding of the
concept of home as they conceive of it. Thus, beyond advancing a relational perspective of and
developing a landscapes of LTC framework from its lived experiences, the dissertation provides a
new perspective of home beyond the house developed from such LTC experiences. Specifically,
the findings contribute a conception of home in LTC from the perspective of staff, family and
residents as a functional, familiar, and relative construct rather than static location. This finding
adds to the geographical scholarship that considers home as a dynamic process beyond the household.

1.6 Qualitative methodology and theoretical orientation

While Chapter Four provides a more-detailed discussion of the methodological approach along with the philosophical orientation espoused to justify and make sense of the information gathered, this section presents a brief introduction and overview of these aspects of the inquiry. That is, the specific orientations, approach, methods and analysis that facilitated the generation of original information for this dissertation are justified in terms of how they led to particular objectives and contributions accomplished by this project.

1.6.1 Theoretical orientation

Underlying the collection of experiential ‘data’ and drawing from classical phenomenological and existential tenets from humanist scholars such as Buttimer, (1976), Ley and Samuels, (1978), Relph, (1976) and Tuan, (1976), this project espouses a broadly humanist ‘locality of being’ ontological approach. In this approach, place and people are inextricably and ontologically coupled insofar as places make people meaningful and people make place knowable (Casey, 2001; Malpas, 2008;). That is, to be is to be somewhere and what a place is, is bound up with how it is experienced by humans. The corresponding object of interest for the methodological aspect of this dissertation, then, is a lived experience or what might be termed a lived emplacement reflecting the subjective experiences of a particular group in and from a particular type of place. To acquire this type of information requires implementation of experiential, empathetic and interpersonal ways of knowing that are guided by underlying personal senses of wonder, humility and reflexivity (Pocock, 1996, Seamon, 1979; Rowles, 1978). Rather than seeking an overarching truth, this project aims to suggest intersubjective truths revealing how people make sense of events around them and render them ‘true’ in their own terms and in concert with their particular environment.
As a result, authenticity of this partial form of information is based not on the verification of an *a priori* causal relationship but upon the quality of the human relationships persistent in the research along with the integrity and honesty of the researcher. Here authenticity further takes the form of intersubjective corroboration where the findings ring true and genuinely move those who participated, other researchers/readers, and the researcher with a sincere sense of empathy and honesty.

### 1.6.2 Methodological design and methods

A qualitative community-based, multi-site case study methodological structure/design was employed to operationalize this philosophical orientation and ultimately inform the collection of information in the form of a lived emplacement in LTC environments informed by PCC (Chapter Four). This design supports the tracing of qualitatively expressed lived experiences/emplacement of a phenomenon (PCC) across and within research sites in the interest of and in partnership with community and research stakeholders. To do so, one-on-one interviews were conducted with staff, residents and family members in three LTC facilities espousing PCC approaches and were bolstered as well as partially informed by observation periods by the researcher in each facility. The specific application of the research tools was largely guided by facility-based suggestions in line with a community-based approach and, as such, differed slightly amongst the participating facilities.

### 1.6.3 Content analysis

The information gathered from the interviews was analyzed according to a content analysis approach, the goal of which was to refine and distill the interview responses to generate a thematic account of the lived experience of environments informed by PCC. This was accomplished specifically through an application of Berg’s (2009) ‘7 stage model’ of a qualitative content analysis process to the information gathered through interviews and with context from observation periods. Employing both inductive and deductive reasoning approaches where, broadly, common themes within participant groups emerged from the responses (inductive) were
set/categorized within an ideologically relevant conceptual framework (deductive) to express the results as direct responses from participants but organized within a meaningful and discipline-specific structure for further refinement based on specific research goals. Through this refinement approach, three emergent themes arose that largely make up an experience of LTC environments informed by PCC: homelike atmosphere, flexibility and relationships. These themes were then discussed in terms of their tension’s experiences by each group in light of the conceptual critiques provided by the salient bodies of literature to inform an expanded understanding and decentering of PCC (Chapters Five and Six).

1.7 Dissertation structure and layout

The following chapter situates this dissertation in the dementia care literature that provides an internal critique of PCC, to ultimately provide conceptual weak spots in PCC, some of which are addressed directly in this dissertation. Chapter Three goes on to situate the project in the field of geographical gerontology from which the Landscapes of LTC framework is developed. Chapter Four then fleshes out the specific methodological approach outlined in an earlier section including the philosophical orientation, research design, access, participant and facility descriptions, methods and analysis. Chapter Five presents the empirical results gathered through the process presented in Chapter Four in an effort to establish emergent themes and depict the lived experience for each group in each facility. This chapter is largely included as a straightforward presentation to ultimately be presented back to the participating facilities and to introduce the emerging themes that will shape the proceeding discussion for a further distillation of the lived experiences. Chapter Six is structured again within the emergent themes; however, it provides the main contribution from the dissertation by focusing on the experiential tensions expressed as pathways to express a relational and tension-based perspective of PCC through a landscape of LTC lens (which itself is expanded by the process). In this chapter, the empirical and experiential tensions expressed act to situate the conceptual critiques and advance a relational understanding of place in the LTC context. Finally, Chapter Seven includes a synthesis of the
results in terms of how the objectives were addressed and what contributions were made. The discussion of each objective also includes the limitations to this approach and suggestions for future research. The chapter concludes with some final thoughts that are reflexive in nature and represent how I have been moved by the research.
Chapter 2 Framing the critique: Person-centred care in the dementia care literature

The discussion in this chapter provides the research context from the perspective of critical dementia care theorists who have made great strides to theoretically critique and move beyond PCC. While PCC has been taken up in LTC, it was borne out of dementia care theory and that is where it is given a more thorough analysis. Since the 1980s there has been a great interest from academics and practitioners alike in how to properly conceptualize dementia (Innes, Kelly and McCabe, 2012). Biomedical approaches that frame dementia as a strictly physical/neurological status have been challenged (Lyman, 1989; Bond, 1992), while a focus on the experiences and identity of people living with dementia along with their ability to provide insight and awareness into their own condition have been brought to the fore (Clare, 2004; Kitwood, 1997). Additionally, interactions among the social sciences, critical gerontology and dementia research have shed light on the social and spatial structures that influence the experience of dementia and the way care practices are imagined and implemented (Innes, 2009).

What is the nature of theory in dementia studies, though? Innes, Kelly and McCabe (2012) note that theory in the dementia studies field refers to “the different starting points, perspectives and approaches…used to describe and understand dementia, and in turn how to operationalise these ideas in the delivery of care or understanding of lived experiences” (p. 16). So, theory refers not only to conceptions of how to understand dementia itself but also how that understanding might be considered good practice.

2.1 The standard paradigm

Innes and others (2012) put forth three foundational perspectives that contribute to our understanding of dementia and justify care approaches with each drawing from a multidisciplinary background: biomedical perspectives, social-psychological perspectives and critical social gerontology. She argues that theory matters in dementia studies and more specifically for a need to appreciate the strengths of each perspective, advocating for a subsequent holistic approach to understanding dementia. The biomedical perspective or the biomedical model
(or the ‘Standard Paradigm’ for Kitwood (1997)), according to Lyman (1989) has three foundational propositions as it pertains to dementia:

- Dementia is a pathological, abnormal condition;
- Dementia is organic in aetiology and progresses through stages;
- Dementia is diagnosed using biomedical assessments.

Before outlining its critiques, it is worth considering the contributions and possibilities for dementia and dementia care arising from this often maligned paradigm. First, presenting dementia as a medical issue provides a straightforward explanation for what is happening to the person living with dementia and a way of coping with the challenges of caring for the person (Bond, 1992). Second, it has been put forth that the medicalization of dementia has led to increased funding for research on mainly Alzheimer’s disease but also other forms of dementia (Fox, 2000). Last, as Innes (2012) tells us, “Biomedical approaches have done much to alert us to the importance of early diagnosis and possible ways to protect against developing dementia in later life” (p. 28). It is clear that framing dementia within a biomedical perspective is important to both acknowledge the physical realities of the diseases(s) and to justify the continued pursuit of understanding and treating them through research and technological medical advancements. The discussion of a cure is one necessarily based on a biomedical understanding of the physical and neurological attributes of dementia and an official diagnosis can bring comfort to those who are confused about what is happening to them or their loved one (Bond, 1992).

Critics note that framing dementia as strictly pathological amounts to the conflation of people living with dementia’s identities and the disease state (Innes, 2012; Kitwood, 1997). Additionally, there is a fine and hazy boundary between what is perceived as normal behaviour and that which can be associated with a psychological disorder (Crisp et al., 2000). Finally, regarding the first premise, it is difficult to distinguish between an individual’s diverse normal behaviours throughout their life and those that can be attributed to the effects of dementia (Lyman, 1989). Indeed, the limitations of the biomedical model have been aptly illustrated by
Harding and Palfrey (1997, p.34) in their summary about what is known about dementia from empirical research as follows: “cause: unknown; diagnosis: very difficult until after death.” Although this comes from research undertaken more than twenty years ago, it is unlikely that the general sentiment would be contested today.

On the second premise, Gubrium (1986) has noted that, as the progression of symptoms is highly variable among individuals, distinct similarities in the experience of disease stages are rarely seen. Similarly, Kitwood (1997) notes that a trust in these a priori stages by carers as ways to explain and predict behaviour leads to immense tension as individuals living with dementia manifest symptoms in diverse and multiple ways throughout the disease progression. Finally, unequal power relationships among doctors, carers and people living with a dementia results from a diagnosis using strictly medical assessments. Such a diagnosis can conflate the person with their disease state leading to justification of dehumanizing practices such as the overuse of chemical restraints which increases the likelihood of agitation of the person living with dementia. Additionally, the medical expectation of further deterioration causes the dementing process to become a pre-determined and self-fulfilling medical prophecy regardless of the individual experience or potential (Bond, 1992; Innes et al., 2012; Lyman, 1989).

With all this said, the key tension underlying biomedical approaches is that they tend to omit the viewpoint or continued capacities of the individual living with a dementia in their conceptualization of the affliction. They are often characterized as ‘decline, decay and deficiency’ models as a result of their focus on the disease progression rather than the person. Largely as a result of a recognition of this fundamental omission, alternate conceptions of dementia based on social-psychological rather than strictly medical perspectives began to arise throughout the late 1980s and early 1990s (Innes, 2012).

2.2 Locating person-centred care

challenged the biomedical model or ‘standard paradigm’ by insisting that an essential ‘self’ (for Sabat) or ‘personhood’ (for Kitwood) remains throughout the dementing process and that it is the role of caregivers to maintain and enhance these remnants of humanity. For these scholars, this maintenance is accomplished through positive social interactions and communication strategies while acknowledging the physical/neurological realities of these types of diseases (Cowdell, 2006; Dewing, 2008). For these modern approaches, the fundamental expansion of the biomedical model is found in the idea that while there are neurological aspects of dementia that should be acknowledged, people living with dementia retain their individual capacities, history, and essence throughout the disease process and it is possible for them to continue to express this provided the requisite knowledge and empathy in the social-psychological environment is in place. Of great importance is the idea that this insistence removes some of the burden of dementing processes from the person living with it and the subsequent justification of humanizing and empathetic care approaches. PCC is the most enduring contribution from this perspective to dementia research and practice to date.

Critical gerontology problematizes the “failure [of PCC] to locate analysis of experiences of individuals within wider social, political, cultural and economic concerns which combine to shape the experiences of individuals and the care that they receive.” (Innes et al., 2012, p. 30) The tension between theory and practice based on an overly individual focus is similar in the two broad fields. While PCC as an application of a social-psychological perspective has done well to provide practitioners with a framework of ethical and humanitarian values, it is not clear whether personal attributes of care workers or organizational structures should be the focus and this confusion is reflected in a lack of pervasive change in care practices (Edvardson et al., 2008; Innes, Macpherson and McCabe, 2006). Indeed, although PCC is often championed in institutions’ mission and philosophy statements, tensions exist when implementing the philosophy into professional practice (Hebblewaith, 2013). Having problematized the context surrounding its emergence and implementation, the internal tensions of PCC will now be outlined
to focus the discussion on suggestions from literature in critical gerontology about why PCC has not either been adequately adopted or conceptualized.

2.3 Person-centred care and its internal tensions

Echoing the critiques laid out from the dementia care field in general, the fundamental tension underlying PCC is that while major national policies have taken up the language of PCC there has not been an equally weighted shift in practice. Indeed, on this disconnect Baldwin and Capstick (2007) note, “there is little to support the claim that Kitwood’s theory of dementia – as a dialectical process in which distal and proximal causes come together resulting in neurological impairment – has been taken up in any significant manner…the very popularity of ‘person-centeredness’ language often conceals a rather superficial engagement with the complexity of Kitwood’s original theories” (p. xxii). In fact, Kitwood (1997) himself warned us of the possibility of his initial formulation being applied haphazardly or in a superficial way, as he notes in his penultimate, and most thorough piece on PCC - Dementia Reconsidered : “It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 [or 2019?] might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures” (pg. 133).

Perhaps it is fitting that although Kitwood’s person-centred approach lies in the crosshairs of this project’s critique, his statement above encapsulates the project’s underlying thrust – to move beyond such glossy mission statements and access what people are experiencing. Though much of this misapplication (or misconception) of PCC can be attributed to external and broader forces as discussed above, there are a number of key internal tensions in Kitwood’s initial formulation that might also help us understand the aspects that require revision or expansion. Kitwood’s ideas are presented in three parts that correspond to the fundamental pieces of PCC: his critique of the standard paradigm; ill-being, well-being and psychological need; and personhood. While critiques found in the ‘personhood’ section provide the most direct source of
expansion for this inquiry, a fulsome outline of Kitwood’s broader theory of dementia in general and his connections between care and well-being provide important context for such a discussion.

2.3.1 Kitwood’s critique of the standard paradigm and the dialectic of dementia

Kitwood’s theory of dementia is presented through a number of publications, mainly (1993, 1996 and 1997). Underlying this theory and mirroring the above biomedical discussion, is a fundamental challenge/critique of an understanding of dementia as an ‘organic mental disorder.’ Based on a strictly physical understanding of the group of diseases, Kitwood argues that most research and practice in dementia takes place through a biomedical and technical paradigm that is deficit focused, therapeutically nihilistic and medically based. He termed this the standard paradigm. He also critiques the standard paradigm for considering dementia mainly through a discussion of the limits to neuropathological research (Baldwin and Capstick, 2007).

Kitwood’s (1987) core argument on the limits of neuropathological research is that the standard paradigm lacks any explanation of why some people experience dementia with very low, or no, neurological damage while others experience dementia with a high degree of neurological damage. Within this core critique Kitwood noted that the standard paradigm is specifically limited by its failure to include psychological factors in its explanation of dementia (1988a) and the subsequent conflation of behavioural/psychological and neurological discourses resulting in a diminished or obscured explanatory ability (1996a). In other words, in its emphasis on neurological or ‘organic’ processes, the standard paradigm justifies the exclusion of contributions from social-psychological aspects that might help provide a more nuanced perspective of the experience. In spite of these internal limitations the standard paradigm prevails.

Kitwood describes three main undesirable outcomes from this continued dominance: the implied marginalization of alternate approaches and resulting limits to our understanding of dementia and ways to provide care; the exclusion of the person with dementia or conflation of person with disease; and the focus on losses rather than continuing capacities which is
represented in images of dementia as “death that leaves the body behind” or “the prison that waits” (Kitwood, 1993b, Kitwood, 1996b).

Further, Kitwood not only expresses a critique of the standard paradigm as a theoretical construct, but also as a contributor to a bleak lived experience as depicted in his often cited (1990a) characterization of what it feels like to live in a facility informed by the standard paradigm:

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You are in a swirling fog, and half-darkness. You are wandering around in a place which seems vaguely familiar and yet you do not know where you are. You cannot make out whether it is night or day, summer or winter. At times the fog clears a little and you can see objects really clearly. Even then, the feeling for their place in a larger pattern of things has gone. You are continually trying to make sense of where you are, but you are overpowered by a kind of dullness and stupidity, you catch hold of a few details but just as you are beginning to get the picture your knowledge slips away and again you are utterly confused. You forget what you are trying to do or your body will not obey your instructions...

Once you were a person who counted, who made a mark on the world. Now you are nothing and good for nothing. A sense of oppression hangs over you, intensifying at times into naked terror, its meaning is that you might be abounded forever, deprived of all loving contact that once sustained you, left to rot and disintegrate into unbeing.
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Kitwood, (1990, pp. 40-41)

It is this type of dehumanizing and hospital-like experience that Kitwood wished to combat through his dialectical understanding of dementia found in PCC.

Kitwood’s reconsideration of dementia (re)frames it as a, “function of the interrelationship between social, psychological and neurological events” (Baldwin and Capstick, 2007, p. 10). This interrelationship represents the root of the dialectic framework for understanding dementia. Further, Kitwood (1990) explains the resulting dementing process in two base premises: it is compounded from the effects of neurological impairment and malignant (undermining) social psychology; and the neurological impairment in an older person attracts itself to a malignant social psychology.

Thus, dementia is to be considered a function of both care and neurological impairment where each of the factors in the dementing equation interact to create and sustain the dementing
process. Kitwood later included social and personal effects such as personality, biography and health to this equation (1993c). As the arrangement of these variables/factors varies amongst individuals Kitwood directs us to emphasize the uniqueness of persons and the individuality of care required to maintain personhood (a concept discussed in the following section).

Kitwood’s alternative approach was initially critiqued for not providing supporting evidence for his claims (Flicker, 1999) and methodologically for providing predominantly anecdotal evidence while not requiring rigorous testing (Adams, 1996; Murphy, 1997). These claims have not undermined Kitwood’s contribution; however, as it is generally agreed that even if he was “ever an arm chair theorist, the arm chair was located firmly in the day-room of a residential home in the midst of people with dementia” (Woods, 1995, p.5).

Beyond specific critiques of the dialectic approach, its core enduring facet is its implication of the environment and other people to the experience of dementia where attention is drawn to problematic parts brought to the caring relationship by the cognitively intact (Kitwood and Bredin, 1992). We will encounter this dialectic approach throughout this section as well as later in the dissertation as it is used loosely to structure my presentation of the experiences of residential care facilities.

2.3.2 Ill-being, well-being in dementia

The second aspect of Kitwood’s formulation of PCC considered here, which stems directly from his dialectic understanding, is the connection between relative well/ill-being and good quality care. To this end, Kitwood’s approach to well/ill-being in dementia can be summed up in three postulates that are adapted here from Baldwin and Capstick (2007):

1. If their psychological needs are met, it is possible for people living with dementia to persist in a relatively high state of well-being. Here intellectual prowess or capacity is not a prerequisite for well-being.
2. Relative ill-being for people living with dementia is a result of numerous factors beyond neuropathology. Quality of care and support available are suggested as particularly
influential variables, highlighting the incendiary notion that kindness and care can be ‘therapeutic’ in the sense that it can actually reverse the dementing process itself as displayed in Kitwood and Bredin’s (1992a) claim that, “as social being is recovered, so mind (in some of its aspects) is restored” (p. 138). This is a controversial claim of ‘remotia’ and one that Kitwood does not continue to put forth in his (1997) most fleshed out publication.

3. The behaviour of people living with dementia is done with purpose and can be understood as meaningful attempts to express a need. Those behaviours that may be viewed through the standard paradigm as problematic would be better understood as expressive indicators of ill-being caused by a lack of psychological support.

According to Kitwood, due to the chronic nature of dementia it cannot ever be viewed as a state of well-being, but as cognition is only part of what it means to be human (personhood) it is still possible to live in relative well-being if other parts are supported. Ill-being in dementia is viewed as a result of negligent and insensitive care practice or as what Kitwood and Bredin (1992a) term a ‘malignant social psychology’ for which Kitwood (1997) provides a number of indicators in the care context such as treachery, infantilization, mockery and disparagement. In contrast, relative well-being is generally equated with the preservation of a psychological concept of personhood, a concept explored in the next section and where much of the room for expansion in his formulation lies.

Kitwood’s thoughts on ill/well-being have also been critiqued mainly for a lack of empirical evidence (Flickr, 1999) and considerable methodological issues (Murphy, 1997). Ultimately, it is enough for this exploration to summarize with Kitwood’s relatively humble claim that “we should care for and respond to the psychological needs of people with dementia because this is the only decent way to treat our fellow human beings…we may hope this makes a difference, although we will have no consistent or abiding evidence for this” (Baldwin and Capstick, 2007, p. 106). Although not necessarily a provocative claim, this is the basis and
justification for providing good care for people living with dementia. It reminds us that even in the presence of a chronic illness such as dementia, there is opportunity for relative well-being by attending to factors that we can control and directs us to his more contested and practice-related concept of personhood.

2.3.3 Personhood: The key source of tension in person-centred care

As the fundamental goal of PCC is its maintenance and promotion, personhood is the core concept for Kitwood’s (1997) conceptualization. Moreover, he notes that beyond the academic or theoretical debates surrounding the concept of personhood, we should recognize how it is inextricably bound with practice such that, “any such theory…should be able to tell us something about the nature and meaning of good dementia care” (Kitwood, 1990b, pg. 14). Due to centrality of this concept to PCC as well as the direct relationship between conceptions of personhood and practice, it is in this section that we encounter the most specific, robust and salient critiques internal to PCC. It is through an engagement with the particular internal tensions in PCC that we might better understand the practical tensions in the lived experience of environments informed by PCC in later chapters thus making room for new developments or expansions.

Drawing from the fields of transcendence, ethics and social-psychology, Kitwood (1997) famously summed up his theory of personhood as “a standing or status bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (pg. 8). Kitwood viewed life itself as sacred and espoused the Kantian proposition that people ought to be treated as ends in themselves rather than as means to some other ends. He puts forth a symbolic interactionist social-psychological perspective of identity where the self is created and preserved mainly through social interactions between and within people (Baldwin and Capstick, 2007; Kitwood, 1997). Further, on the type of relationship Kitwood is promoting, he elicits Martin Buber’s spiritual notion of ‘I-Thou’ relationships (as opposed to the more detached
‘I-It’) where to be a person is to be addressed as Thou by another: an expression based on being in the present, compassion, openness and tenderness (Kitwood, 1994).

This conceptualization of personhood offers a number of possibilities that have a growing empirical affirmation and a longstanding implication for dementia care through PCC applications. First, though his view of the self/personhood remaining throughout the progression of dementia is relatively uncontested now, when Kitwood (1990a, 1993d; Kitwood and Bredin, 1992a) was mounting his theory the debate was dominated by those arguing for a biomedical, capacity-based perspective on personhood where personhood is necessarily lost with the onset and progression of dementia (for example, see Brock, 1993). Personhood as understood in PCC clearly contrasts this view by focusing on continuing capacities and the unique aspects of self that remains in individuals until death. Much of the perceived loss of self as viewed in PCC is instead attributed to the negative ways that others treat and respond to the person living with dementia, thus shifting some of the burden of the disease (e.g., Sabat and Harre, 1992). Second and following the idea that people living with dementia retain a sense of self along with certain capacities, it is now broadly accepted that it is possible and necessary to engage directly with people living with dementia if we wish to understand their experience and needs (Downs, 1997; Goldsmith, 1996; Wilkinson, 2002). This point is expanded in Chapter Four to include some of the considerations made when conducting this type of research but of note here is that the assumption that people living with dementia have the capacity to express their experiences and the accompanying responsibility for researchers to create a discursive space to elicit such experiences is made possible from Kitwood’s initial formulation of personhood and PCC’s stated role to maintain and enhance it. Finally, the relational basis of Kitwood’s conception of personhood points to the importance and possibilities of conversations as care. That is, the social interactions between people living with dementia and their care partners are reflexive and meaningful where people living with dementia are viewed as active contributors as they have sustained their
communicative capacities (Hamilton, 2005; Ryan et al., 2005; Sabat, 2001). As such, much can be learnt from exploring social interactions.

It is generally agreed upon that while Kitwood’s work on personhood has unveiled many novel and constructive pathways to understanding and caring for people living with dementia, it is an unfinished project mainly due to his untimely death (Baldwin and Capstick, 2007). Indeed, Baldwin and Capstick (2007) note, “[Kitwood] would not have wanted his theories and arguments to be embraced uncritically but to be engaged with, developed and put into practice for the benefit of people living with dementia and their carers” (p. 181). It is in that spirit that this project was conceptualized and how it proceeds, starting with the key critiques and conceptual pathways they reveal. Four core criticisms have been levelled at Kitwood’s conception of personhood as taken up in PCC:

1. Although it is based on a social-interactionalist relationality, Kitwood’s theory of personhood seems to conceive of relationality as a one-way exchange where personhood can only be bestowed by others unto those living with dementia and not the other way around (Nolan et al., 2002; O’Connor et al., 2007[Mendeley]). The focus of the theory and consequently of PCC is solely on imbuing the person living with dementia with personhood, effectively omitting those caring for that person from the equation other than as providers. As a result, this is said to be an over-individualistic and lop-sided theory that is applied to the possible detriment of care partners’ personhood and to the increased vulnerability and dependency of people living with dementia.

2. While a focus on continuing capacities and preservation of the personhood has done much to enhance the quality of life for people living with dementia, losing sight of the realities of aging and the disease progression may impede the grieving process for family members (Baldwin and Capstick, 2007; Davis, 2004). An enhanced burden or feelings of guilt may arise from family members who focus all of their efforts to preserve this precarious sense of personhood of their loved one living with dementia.
3. Echoing the above criticisms of certain approaches to long-term care, Bartlett and O’Connor (2007) note that Kitwood’s conception of personhood brackets or ignores wider economic, social and political contexts that interact with individual characteristics to shape people’s experiences and decisions. As a result, applications of Kitwood’s theory of personhood tend to have a narrow focus on the individual and her/his immediate environment. Devoid of such considerations, critics note, personhood has limited potential to bring about meaningful change.

4. As with most of Kitwood’s theories, his conception of personhood is not sufficiently supported with empirical evidence and is thus still a work in progress (which he himself noted) (Adams, 1996; Adams and Bartlett, 2003).

Based on these core criticisms along with further and more recent empirical and theoretical developments, Baldwin and Capstick (2007) identify four aspects of personhood that are absent or underdeveloped in Kitwood’s formulation and that have potential to expand the theory in a meaningful way: personhood as process; embodied personhood; personhood and citizenship; and personhood and place.

*Personhood as Process (relational-centred care)*

Rather than viewing personhood as a fixed/static outcome, authors such as Davis (2004) and Purves (2006) have suggested personhood be re-conceptualized as a relational process involving both carers and people living with dementia. The underlying issue from Kitwood’s account of personhood is that it blurs the distinction between ethics and social psychology where the former imbues a static moral standing to all people and the latter denotes a dynamic social process (Higgs and Gilleard, 2016). In other words, although moral status as a person is sustained, people’s roles, relationships and identity change through time and space whether or not they develop dementia and there is no mechanism in PCC to account for such inevitable personal developments. This disconnect, most noticeably in family care settings, can be the cause of much guilt and confusion in the grieving process (Davis, 2004). Analysing personhood as a process...
may reveal much about how roles and social positionings are contextually bound, always subject to contestation and, as such, dynamic processes even in the face of progressing dementia (O’Connor et al., 2007, Purves, 2006). It is through this expansion of personhood as a process that scholars have endeavoured to rename PCC ‘relational-centred care’(Adams & Gardiner, 2005; Nolan et al., 2002; Nolan, et al., 2004), aiming to capture, ‘the interdependencies and reciprocities that underpin caring relationships’ (Nolan et al., 2002, p. 203). As a result there is space to further develop the theory of personhood in PCC through analysis of its reciprocal nature (how both caregivers and those living with dementia construct and navigate positionings throughout the disease process) and its developmental aspects (while the moral status of people living with dementia does not change, their relationships, roles and positions with respect to their loved ones do).

Embodyed personhood

Kitwood’s initial thrust to redefine dementia in social-psychological terms and subsequent framing of personhood as a strictly social outcome had the effect of relegating the body to the role of static disease carrier. He articulated the body as essentially separate from and devoid of social processes by framing it as being strictly in realm of natural science where physical processes occur in the body and social processes occur elsewhere (Kontos and Martin, 2013; Baldwin and Capstick, 2007). This view is challenged by many scholars including Davis, 2004; Kontos, 2004; Kontos and Martin, 2013; Kontos et al., 2016; Martin et al., 2013; Twigg and Buse, 2013 who view Kitwood’s theory as essential but deficient in its ability to capture all of the ways personhood can be expressed and retained. Specifically, these authors explore various ways that personhood is constituted in and through the body. Beyond its biological/neurological components, in conducting everyday practices the body constantly presents us with pre-reflective insights about one’s lived experience. Every day, taken for granted bodily practices such as dressing (Twigg and Buse, 2013), wandering (Downs, 2013) and expressions of sexuality (Kontos et al., 2016) while seemingly mundane, should be viewed as meaningful expressions of
personhood or lack thereof. Further, these studies seek to situate the body in its wider social, economic and political context to make sense of how experiences and their expressions are interrelated with broader phenomena (Kontos and Martin, 2013). Overall, this expansion of PCC stems from a recognition of “the importance of primordial and socio-cultural dispositions of the body as agential sources of self-expression” (Kontos et al., 2016, pg. 319). Moreover, researchers have sought to include an embodied dimension with the aforementioned relationality used to better describe personhood as a process.

Through an embodiment lens, relationality is to be understood not just as a social psychological process between caregiver and person living with dementia but rather as a “primordial and socio-cultural disposition of the body as agential sources of self-expression,” with such aspects of personhood as a primary basis for interactions and communicative practices for persons living with dementia (Kontos, et al., 2016, pg. 319). Expanding relational personhood in this way captures the importance of expressed emotions as well as pre-reflective and socio-cultural dispositions of the body as key sources of self-expression, which are then said to be important aspects of broadening understanding of relationality beyond the more immediate ‘relational-centred care’ (Kontos, 2012). Exploring ways in which personhood is embodied in a relational manor thus presents a great deal of potential for understanding the experience of dementia and subsequent adjustments in care practice beyond Kitwood’s initial formulation where the social-psychological self is removed from the centre of the inquiry to form part of a broader constellation of embodied relational experiences.

**Personhood and Citizenship**

Arising from the foundational critiques that Kitwood’s personhood is essentially an apolitical concept that tends to focus too narrowly on individuals and care partners in their immediate environment, researchers have explored ways to consider how individual experiences of dementia are structured within a broader socio-political context (Baldwin and Capstick, 2007; Baldwin and Greason, 2016; Kontos et al, 2016). While the push towards a focus on personhood
as conceptualised by Kitwood has indeed helped to improve much dementia care practice, this focus has been centred around micro level interactions and did not provide the language for discussing people’s experiences in terms of the impact of social structures related to age, disability, gender, ethnicity and class (Bartlett & O’Connor, 2007). Put simply, the personhood of people living with dementia, “remained dependent upon the good auspices of the cognitively intact, rather than a non-negotiable, fundamental status, not dependent upon others for affirmation” (Baldwin and Greason, 2016, pg. 219).

In an effort to extend conceptions of personhood into the political arena, researchers have suggested that a lens of ‘citizenship’ might be more appropriate as a way to understand and respond to socio-cultural discrimination that often accompanies dementia. Citizenship is said to imply agency and multiple social identities of people living with dementia and force us to relocate experiences such as disempowerment and discrimination from individual/personal issues, to outcomes of wider social relations (Downs, 1997; Kontos et al., 2016).

A recent example that builds on the previous two concepts come from Kontos et al. (2016). In this study Kontos et al. employ tenets of embodied selfhood/personhood and relationality to develop a ‘relational citizenship’ model for understanding experiences of dementia care. They argue that “embodied self-expression must be recognized as fundamental to the human condition and thus supported through a matrix of human rights” where the sexual rights of individuals living with dementia are proposed as integral to such embodied self-expression (pg. 319). This framework (or ethic as Kontos et al. describe it) is then used to discuss the cultural (prevailing attitudes) and organizational (limiting oppressive practices and providing opportunities for sexual expression) barriers and opportunities to sexual rights being upheld for people living with dementia in LTC. Repositioning people living with dementia as active citizens rather than as tragic victims of disease in such a way gives them a voice in their representation beyond micro-level, immediate interactions and as such provides a great possibility for further expansion of personhood and its application in LTC.
Personhood and Place

The final opportunity to further develop Kitwood’s version of personhood presents the most direct integration with geographical approaches. That is considering how personhood is “founded, undermined or supported by our relationship with place, particularly our sense of home” (Baldwin and Capstick, 2007, pg. 186). Acknowledging the influence that particular recollections of home have on the preservation of our self-identity and sense of belonging, researchers such as Chaudhury (1999, 2003) and Frank (2005) have considered the relationship between evolving memories of home for people living with dementia and generally the relationship between self, personhood and place for people living with dementia. Stemming from empirical studies on memories of home in people living with dementia in LTC facilities, investigating the real and imagined concept of home is said to have great potential to elicit information about the sense of self that is often hidden behind the realities of the disease. Although recognized as an important development in PCC, the nature of the relationship between self and place in the experience of dementia and the sense of home as a guiding care principle still requires much work according to Baldwin and Capstick (2007). Although maintaining a home-like environment is often offered as an indicator of PCC and other individual focused approaches (Chappell et al., 2007), the concept of home in this context is more complex and nuanced than often assumed to be within such approaches and in policy that promotes them. As mentioned, this is a topic that is well suited to a geographic lens where place is a core concept.

2.4 Conceptual contributions to dementia studies

Central to this dissertation are the relational concepts of place and care in the LTC context that have been developed in critical gerontology as critiques of PCC. The contributions of this dissertation are the bolstering or advancing of existing arguments towards relationship-centred care by framing the experiences of place in the Ontario LTC context as relationally constitutive and discussing the tensions arising in LTC experiences as outcomes of static notions of place and/or care in this context. In doing so, the dissertation also addresses the final critique of PCC lacking a
sense of place by engaging explicitly with home as a core concept in the experience of LTC in light of the extensive consideration this concept has been given as a distinct type of place in geographical scholarship. Recognizing that where care happens matters, concepts of place and care are viewed as inextricably linked in the landscapes of care framework that is applied to experiences of LTC in this dissertation. Thus, furthering a relational approach to place similarly advances a relational approach to care in the LTC context as suggested by these critical gerontological scholars.

What this dissertation does not address, that have been developed extensively in critical gerontology and dementia care studies, are concepts of embodiment and citizenship as they relate to understanding and ultimately moving beyond PCC. The theoretical shift from personhood to citizenship noted above is premised on both a relational and embodied understanding of the experience of care. This ontological shift is a promising alternative to PCC that is well developed in critical gerontology, but the methodological approach employed in this dissertation is not sensitive to embodied aspects of experience and as such it is beyond the scope of this project. These concepts of embodiment and citizenship will be revisited in a discussion of the limitations of this dissertation in the concluding chapter as suggestions for future research from the perspective of geographical gerontology. Additionally, while it does consider basic structural elements as parts of the relational experience of LTC environments, this dissertation does not apply a critical structural lens in its analysis. The focus of this dissertation is the experience of PCC approaches to LTC at the facility-level, emphasizing those facility-based issues that accompany PCC to advance a relational conception of place and care in general. A critical structural lens such as the feminist political economy one noted in Chapter One is important to gain insight into wider contexts that affect experiences of care but is beyond the conceptual scope of this project. As such, I will also return to a discussion of structural issues in a discussion of the limitations of this dissertation in the concluding chapter.

While critical gerontological scholars have made great theoretical strides to move beyond PCC in the LTC context, this particular topic has seen relatively little attention in geographical
gerontology to date. As a broader contribution, this dissertation makes an incremental push towards interdisciplinary collaboration by aligning concepts of care and place in the LTC context through a shared espousal of relationality as a conceptual bridge. Additionally, in spite of the existing theoretical critiques, PCC remains as a policy directive for LTC in Ontario and tensions remain in its lived experience. As a result, it remains an important directive to continue to advance the existing arguments for alternative relational approaches through a complementary place-based theoretical lens and situated in practical lived experiences of LTC to further the argument for a shift in how we approach LTC in practice.
Chapter 3 Framing a landscape of long-term care: Geographical gerontology and experiences of person-centred care

Having presented the conceptual and practical critique, the previous chapter defined a number of gaps that represent room for expansion of PCC. This chapter presents an approach to bridging these gaps through an engagement with the discipline of geographical gerontology. The main goal of this chapter is to situate the critiques of PCC and the conceptual gaps for expansion within the conceptual breadth of geographical gerontology. Considering the core concept of place as relational and embodied, the chapter presents a spatially-sensitive framework through which to view the empirical findings in an effort to unearth new understandings of the experience of PCC that emerge from such a place-based analysis. A relational perspective is followed and bolstered by an internal, embodied perspective to structure a landscape of a LTC framework that highlights concepts of relationality and embodiment which were found to represent possibilities for expansion of PCC in the previous chapter. Ultimately, this framework informed by scholars in geographical gerontology will be adopted to focus and make sense of the experiential tensions arising from LTC environments informed by PCC to contribute to the construction of a landscape of LTC and, in doing so, inform an expanded understanding of PCC itself.

3.1 Geographical gerontology

This chapter sets out with a question adapted from Peace et al. (2006) that I understand as being at the core of any geographical perspective on ageing: How does where you are affect how you are? And how does this relationship change in later life? To expand on or meaningfully answer these questions requires an engagement with the key terms where (place), how (health), and later life (ageing) as well as a unit of observation or scale to encapsulate the inquiry. Interestingly, while these constructs are clearly in the domain of geographical thinking, the quotation inferring their importance comes from scholarship firmly located in environmental and social gerontology. This type of multidisciplinary interaction and conceptual cross-over, rather
than being ignored or viewed as detracting from either field, lies at the heart of and is welcomed by scholars in the burgeoning field of geographical gerontology.

Emerging broadly through the union of the well-established traditions of geographies of ageing (see: Rowles, 1978; Harper and Laws, 1995; Hodge, 2018; Skinner et al., 2015) and the relatively recently spatially concerned social gerontology (Wiles, 2005; Cutchin, 2009; Evans and Wiles, 2013) geographical gerontology embraces its interdisciplinary leanings to apply geographical perspectives, concepts and approaches to the study of ageing, old age and older populations (Skinner et al., 2018). Figure 3.1 shows the broad disciplinary scope of the field with respect to salient geographic and gerontological branches that interact to guide its development. This depiction illustrates the breadth of geographical approaches and perspectives that the field draws upon to understand, depict and expand upon gerontological issues.

Within this broad disciplinary structure the general substantive focus of geographical gerontology spans from the spatial patterns of demographic ageing, movement and migration of older adults, health care services and infrastructure, living arrangements and environments of older people, to the consideration of place in experiences of ageing, health care and well-being along with the ways such experiences are represented and embodied (Andrews et al., 2009; Skinner et al., 2018). While interdisciplinary in nature, Skinner et al., in their recent (2018) comprehensive overview of the discipline, note that geographical gerontology provides distinct contributions to the study of ageing through an “emphasis [on] the importance of scale, place and space in building our understanding of the processes and outcomes, representations and experiences of ageing” (pg.6). For example, scholars in the field of environmental gerontology draw on place as an environmental theme, but their understanding of the concept is informed largely by perspectives from psychology (Scheidt and Schwartz, 2013; Wahl and Weisman, 2003). The resulting psychosocial considerations of place, while informative in their own right, are bolstered through an engagement with the breadth and depth of geographical perspectives on
this core concept, while geographical perspectives benefit with such an influx of psychological thought (Skinner et al., 2018).

Indeed, as Cutchin (2009) notes, “the environmental gerontology tradition has become the dominant mode of geographical discourse within gerontology at the expense of a broader conception of geographical gerontology suggested by geographers.” (pg. 440) Here Cutchin is further emphasizing the point that gerontology might benefit from a further injection of place that is more thoroughly analyzed as a core concept in geography.

**Figure 3.1 Scope of Geographical Gerontology**

![Geographical Gerontology Diagram](image)

Adapted from Skinner et al., (2018, pg 5)

To situate this project within the field of geographical gerontology this discussion focuses on how the discipline and its salient substantive topics for this inquiry have engaged with relatiornality and embodiment as these concepts underlay much of the critiques of PCC and its applications in the previous chapter. Just as critiques from LTC call for a ‘relational ethos of care’ and those from dementia care, a move towards personhood and care a relational processes, there
has been a strong push towards a relational understanding of place with respect to older adults and their wellbeing that can bridge these fields of inquiry in an effort to (re) frame the empirical findings. As such, this relational understanding of place, ageing and health is aligned with the previously stated critiques of PCC from LTC and dementia care to frame the empirical tensions in later chapters in a move towards an expanded, spatially sensitive understanding of experiences of PCC-informed LTC environments.

3.2 Relational conceptions of place

A relatively recent ‘relational turn’ in human geography informed by geographic writers such as Massey (1994, 2005), Amin (2002, 2004), Thrift (1996, 1999) and Harvey (1993, 1996) has brought much attention to the various ways in which the core concepts of space and place can be understood as emergent, encountered, performed and fluid entities (Jones, 2009; Darling, 2009). Rather than discrete and static isolated areas or fixed centres of social meaning, spaces and places come to exist instantaneously through interactions with interrelated networks of spaces and places, or as Jones (2009) puts it, “…objects are space, space is objects, and moreover objects can be understood only in relation to other objects – with all this being a perpetual becoming of heterogeneous networks and events that connect internal spatiotemporal relations” (pg. 491). Thinking relationally then, means to view place as a dynamic process rather than a fixed spatial container; one that is constantly amended and contested through the influx of a multitude of material, emotional and symbolic influences (Darling, 2009). There is no spatial or temporal permanence to this conception of place as its emergence is always subject to the ebbs and flows of such influences resulting in an unstable relational entity that is, “highly permeable, fluid and networked at multiple scales” (Andrews et al., 2012, pg. 1339). To summarize, Table 3.1 below shows Wiles’ (2005) insightful six-pronged depiction of place as it is conceptualized relationally in geographical gerontology.
Table 3.1: The relational conception of place in geographical gerontology

<table>
<thead>
<tr>
<th>• Places are processes</th>
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</thead>
<tbody>
<tr>
<td>• Places are subject to ongoing negotiation</td>
</tr>
<tr>
<td>• There are many different experiences and contested interpretations of places (some of these may compete or conflict)</td>
</tr>
<tr>
<td>• Power relations are expressed through, and shape, places</td>
</tr>
<tr>
<td>• Places are interrelated – to other places, at different scales, at different times</td>
</tr>
<tr>
<td>• Places are simultaneously material/physical and symbolic and social</td>
</tr>
</tbody>
</table>

Adapted from Wiles (2005, pg 101)

Although a fully-fledged and homogeneous ‘relational geography of ageing’ has yet to be documented, relational perspectives of space and place have been applied substantively to topics covered in geographical gerontology in many interrelated ways (see: Skinner et al., 2018 chapter one for a fuller discussion; Cutchin, 2005; Wiles et al., 2009; Milligan and Wiles, 2010; Gustaffson, 2001; Andrews, 2017). As this project is specifically concerning experiences of care, I will adopt a ‘landscapes of care’ framework as conceptualized by Milligan and Wiles (2010) to the empirical findings in an effort to inject the experiences of care with a relational sensitivity to place while subsequently building on this framework through incorporating novel empirical findings from this specific group.

3.3 Landscapes of (long-term) care

The concept of landscape infers and emphasizes the spatially and temporally relational properties of places, invoking notions of diverse features interacting in a way that tells a story or paints an image of experience as greater than the sum of its parts. Reflecting and building upon prior geographic work regarding deinstitutionalization that focused on the ‘landscapes of despair’ arising from restructuring processes (Dear and Wolch, 1987; Gleeson and Kearns, 2001) as well as Gesler’s (1992) concept of ‘therapeutic landscapes’ that pointed us to the intrinsic healing properties of certain places along with those potentially unhealthy elements or how places can be intrinsically untherapeutic (also see Williams, 2007), a landscapes of care framework refers to “the complex embodied and organizational spatialities that emerge from and through the relationships of care…encapsulating the spatial manifestation[s] of care within and across
interconnected scales and the ways in which care is woven through the fabric of particular social spaces” (Milligan and Wiles, 2010, pg. 740). Underlying this relational approach is a recognition that the experience of care is deeply influenced by where it takes place and that such places of care are interrelated in complex ways at many scales all at once while constantly coming into being (Wiles et al., 2012, Zhou, 2012; Dyck et al., 2005) or as Milligan and Wiles (2010) note, “care and care relationships are located in, shaped by, and shape particular spaces and places that stretch from the local to the global” (pg. 736). Adopting this approach, then, involves contextualizing experiences or spatialities of care in terms of their transactions with the surrounding social and political-economic contexts functioning at the level of the individual or wider society, and in public or private arenas. In other words, mapping a particular materialization of care through its socio-spatial relationships with interrelated spatialities from the intimate, to the global.

Although the concept of landscapes of care has been taken up widely in geographical gerontology there is a dearth of perspectives focusing on experiences of LTC at a facility level. This is exemplified by the lack of facility level as a scale of inquiry in Skinner and et al. (2018) comprehensive review of the discipline to date which includes the surrounding and internal: global, national, urban/rural, community, home and individual/embodied scales. Exceptions such as Dupuis et al. (2016), Kontos (2012), Milligan (2005 and 2009) and Peace et al. (2006) exist but LTC remains a relatively undiscovered landscape of care in geographical gerontology or at least relatively unsynthesized as a substantive branch. This relative lack of engagement may be due to the prominence of ageing in place (henceforth: AIP) as a policy initiative coupled with geography and gerontology’s prolonged exuberance for the concept of home (although see Rapaport, 1995 for a critique of this exuberance from environmental gerontology). Moreover and to help justify the approach for this project specifically, while framing the experiences of LTC and PCC within a relationally and spatially sensitive lens such as landscapes of care contributes to the ‘placing’ of such experiences, at the same time the experiences themselves along with
perspectives from related disciplines previously stated inform the construction of a novel geographical framework that might be called a ‘landscape of long-term care.’ In that sense, this approach/framework is at the crux of the conceptual goals for this project as a means to span disciplinary boundaries to contribute to a conceptual model based on under-explored perspectives of care while at the same time providing a new geographic perspective through which to explore those experiences.

As a landscape of LTC framework from which to directly draw from has not been constructed (this is a core contribution of this project), the approach here is to illuminate the surrounding landscapes of care that shape, are shaped by, and encompass such institutional experiences of care. Colouring in the surrounding care constellations around the institutional perspective this way provides a foundation for analysis to flesh out a fulsome landscape of LTC based on empirical findings and how they both mark and are marked by interrelated care spatialities. Notably, this is in itself a relational endeavour, recognizing how spatialities at various scales interact through time to create and emerge from particular experiences of LTC. Specifically, this section considers the concept of home and home care, beginning with how it is conceived through the pervasive concept of ageing in place.

3.3.1 Surrounding policy perspective – Ageing in place and home

A concept that has (re)gained much momentum in health and LTC policy over the past two decades, ageing in place (AIP) can be defined simply as, “remaining living in the home or community, with some level of independence, rather than in residential care” (Davey, et al., 2004, p. 133). It is often viewed as the ideal approach to LTC for older adults to foster independence, autonomy, and connection to social supports (e.g., Keeling, 1999; Lawler, 2001). Additionally, it is desired by policy makers, health providers, and by many older adults themselves for its perceived economic benefits as the World Health Organization (2007) recognizes that having people remain in their homes and communities for as long as possible avoids the costlier option of institutional care. There is a generalized sense of support for the idea
of care that takes place in a home environment as evidenced by its recognition in the health care systems of many Western industrialized countries (Milligan, 2009; Naylor, 1997; Williams, 1996). As a policy and ideology, AIP is built on the premise that the home is the best place to provide care and support for older adults in a way that will support their independence for as long as possible. This is exemplified by Hodge (2008) who tells us, “with seniors, the importance of staying in one’s own home is heightened because of the security it represents, the memories it holds, and its proximity to friends and familiar neighborhoods” (pg. 227).

AIP is by no means a new approach to the provision of health and LTC as even in 1997 Stricklin termed it a “back to the future” movement that has existed for more than a century. There has, however, been a marked recent emphasis on or shift towards AIP in policy due to certain demographic, social, and economic conditions. First, demand for home care is increasing in most Western Industrialized nations due to the rapidly increasing proportion of older adults and improving life expectancy for those with a chronic illness (Hodge, 2008). People are generally living to a much older age than was previously the case and subsequently the disease and illnesses associated with older age are more prevalent. At the same time there is a growing number of older adults who are relatively healthy and do not require or desire to be relocated to an institutional setting such as a residential care facility or nursing home (Wiles, 2005a). This demographic context does not necessarily directly lead to a focus on AIP and home care, but the rapid aging of populations places pressure on policy makers to restructure the way that health and LTC is delivered. Second, parallel to the demographic shift has been a social shift in the way that health is viewed.

Previously thought of as mainly a physical lack of disease, health has been reimagined as a more holistic social, psychological and physical state of wellbeing (Curtis, 2010). This has led to a general mistrust in institutional care mainly for its perceived and historical (in)ability to account for the person as a whole. The prevailing attitude is that LTC facilities focus entirely on efficiency stemming from their adherence to the medical model of health and disease. They are
often seen as being devoid of the meaning and attachment that can support an overall quality of life which is then viewed as being best accounted for by the older person continuing to inhabit their home. In sum, Andrews (2009) tells us that for many people, “it is posited that regardless of whether quality standards can be improved, residential facilities will always carry negative associations that further marginalize older people through their association with them” (pg. 34).

In response to the changing demographic and social context there have been reforms to welfare state provision in many Western Industrialized countries in terms of who is responsible for the delivery of health care services for older adults and how to most efficiently provide care to this group in the face of financial pressures (Wiles, 2005a; Milligan, 2009). One outcome of these changes in formal care services is the closure of many institutional care environments for older adults (Ward-Griffin and Marshall, 2003). The key element of this shift is a general trend towards decentralization of responsibility and control over services from national level to community-based organizations and individuals whereby, “Neoliberal regimes have sought to elevate the role of the citizen consumer, emphasizing not just individual rights, but also citizen responsibilities for their own health and welfare” (Milligan, 2009, pg. 12). As a result of this shift towards individual responsibility underpinned and reflected by an ideology of AIP, the home has emerged as a key site for the provision and consumption of care for older adults (Milligan, 2015; Wiles, 2005).

3.3.2 Home and home care

Homes can be viewed as both material and symbolic entities that are continuously (re)shaped through changes in the individual occupant’s life as well as the social and political context within which it is set (Cloutier et al., 2015; Oswald and Wahl, 2005; Skinner et al., 2015). As a special type of place, geographers Chaudhury and Rowles (2005) note that, “it is widely accepted that the home provides a sense of identity, a locus of security, and a point of centering and orientation in relation to a chaotic world beyond the threshold” (pg.3). The idea of home as an identity centerpiece is also translated as a sense of positive attachment that people feel to the
experiences, memories and expectations embodied within the perception and experience of home (Rubenstein, 1989).

Although the home is often imagined in these ideal expressions, the lived experience of home may not always match this ideal (Wiles, 2005). Indeed, not all homes are physically, socially, or emotionally equal in their ability to promote this positive sense of attachment. For some the meaning of home may represent a site of fear, neglect and even violence (Milligan, 2009). Where this is the case, the experience of relocation may result in improved well-being. Moreover, home as a concept is rich with meaning and contestation beyond what is typically captured in its policy depictions. This idea is captured by Cloutier et al., (2015) where, following Oswald and Wahl’s (2005) layered geographical depiction of home as a physical, social and emotional construct, they argue that “the home space is a ‘rich territory,’ and a far more complex and multi-layered context for understanding relationship-building beyond its significance as a social and policy space” (pg. 769).

Possibly just as crucial as the reasons for living at home is the negative imagery of institutions as symbolically as strong and suggestive as that of home. Although many institutions have moved away from the medical model of care, they continue to conjure up ideas of a loss of independence, autonomy and privacy as imagined spaces (Wiles, 2005). Ruddick (1994) (as cited in Andrews 2005) notes that for many people the difference lies in a perception dichotomy of the perceived experiences where one is either living well at home or waiting to die in an institution. To this point, Andrews (2009) comments that, “researchers who criticize residential settings often ignore the quality of older people’s lives prior to them moving into such places. They argue that institutionalization occurs due to need regardless of the care setting, and residential settings cannot be blamed for generating dependency in older age” (pg. 34). As well, the work of Brown (2003) suggests that while older adults may initially prefer to be cared for by informal carers in the home, contrary to expectations, as levels of care intensify many would prefer to be cared for elsewhere. In other words, the nature of home changes according to its relationship with the
individual and society. Nevertheless, policymakers and service providers have continued to convey home as the preferred site of care (Milligan, 2015; Anderson, 2001).

The meaning of home is further augmented by reconciling it as a place of care that may have the effect of blurring the boundaries between home and institution. This is expressed by Milligan (2009) who notes that “the differing requirements of home and work for older people, informal and formal caregivers mean that the physical and symbolic meaning of home must constantly be negotiated as both a site of care and of social and personal life” (pg. 72). Home is not a static, neutral container. It is a dynamic, negotiated and contested space and its meaning is further blurred when it becomes the site of care (Milligan, 2015).

In their study of the disruption of the meaning of home for older adults as they come into contact with home care, Angus, et al. (2005) discussed three main points of tension: the politics of aesthetics, ordering the home and transcending the limitation of home. On the politics of aesthetics, the researchers found that due to the formal mandates of efficiency, cleanliness, standardization and fiscal restriction, objects associated with healthcare in the home may interfere with the comfort and sensory enjoyment previously afforded in the home space. Additionally, medical devices associated with home care can symbolically and physically represent an unwelcome shift to an environment of disability or/and dependency. The physical equipment and alterations that are often required to properly carry out home care are a constant reminder of declines in health that can act to reshape the home as a place of medical intervention rather than comfort or independence. On ordering the home, the researchers note that “[I]llness and physical impairment may limit an individual’s capacity to perform tasks related to cleaning and tidying, but home care services focus more intently on care of the ailing body than on maintenance of the home” (pg.173). The loss of ability to shape the physical environment reflects the shaky nature of the older adult’s social position, while the care worker is bound by occupational health and safety regulations. As a result, the older adult’s positive attachment to the home can no longer be
assumed. In short, home care service provision can act to further disrupt the idealized relationship between older adults and their home.

Considering this in terms of the earlier discussion about the home cast as mutually exclusive to relocation to institutions, Milligan (2009) notes that “this [complexity] raises questions about institutionalization of the home and the extent to which AIP is shifting the meaning of home such that it comes to represent just another part of the extitution” (pg. 76). Indeed, when taking into account such uncertainties inherent within older people’s and family carers’ relationships with the home and how these can change over time and with increasing frailty, it no longer seems appropriate to blindly accept the premise that the home is necessarily the best place to care and provide support for older adults (Milligan, 2015).

As discussed in the previous LTC section, on a broader structural level, an ideological turn towards AIP that can arguably be justified through an uptake of the family model of social care has contributed to an increasing shift in health policies away from state dependency models in favor of individual and family reliance (Andrews and Phillips, 2005; Armstrong and Braedley, 2013; Milligan, 2015). Inherent within this turn are assumptions about the nature of the family in modern-day society and its willingness and ability to take on elevated caring responsibilities. To this end, AIP as a guide for healthcare restructuring can lead to two disturbing and inter-related trends in healthcare provision: private informalization and informal privatization.

The home and everything that occurs within it have traditionally been viewed as existing in the private sphere. As the responsibility for care shifts towards unpaid and informal caregivers in their homes and away from the state, it becomes less visible and less subject to contestation and opposition than shifts or cutbacks in more public arenas such as hospital closures (Armstrong and Armstrong, 2001; Milligan, 2009; Milligan, 2015). This situation is characterized as a ‘private informalization’ of care where individuals must fend for themselves in the face of changes brought about by aging. At the same time, Wiles (2005a) also recognize that most home care is provided on an unpaid basis by friends and/or family members who may be doing so by
necessity rather than by choice. This corresponding trend is characterized as an ‘informal
privatization’ of care services. Together these trends pile a large amount of financial, physical and
emotional burden onto families in the context of care (Armstrong and Braedley, 2013; Milligan,
2009).

To address these conceptual issues relating to a static depiction of ‘home’ and a focus on
individual/families for the responsibility of care, researchers in geographical gerontology have
espoused variations of a relational understanding of ‘home’ that consider the ways that its
experience is bound up in and emerges from transactions with interrelated networks. Specifically,
this project will apply Martin-Matthews and Cloutier’s recent (2018) consideration of particular
relational properties that contextualize home as a site of care to its contribution to a landscape of
LTC.

3.3 Relational properties of home: Framing a landscape of LTC

To apply the concept of relationality to the proposed construction of a landscape of LTC
it is necessary first to frame the relational context(s) of care at home to eventually extend this
framework to make sense of the experiences of LTC in the following chapters. For this framing
project, the underlying question might well be: which forces, characterized as relational
properties, shape the experience of home as a site of care and how then do these broader
structural forces shape the everyday contexts in which care is delivered and received? (Cloutier et
al., 2015; Martin-Matthews and Cloutier, 2018).

Drawing from the findings of the Nexus Project, an ongoing, national-scale and decades-
long research project on home care in Canada, and applying a relational ethics/space lens from
Sociology (specifically from Bergdorff and Dossetor (2005)), Martin-Matthews and Cloutier
adopted three foundational forces viewed as relational properties that impact the experience of
home as a site of care and provide a framework for this aspect of the analysis: collectivity,
contingency and cultural diversity. Each of these relational properties effect and reflect both the
contested and collaborative aspects of care at home, providing a nuanced and transactional
perspective to be applied to the institutional experiences and tensions gleaned from research. Considering the ways that, according to Martin-Matthews and Cloutier (2018), “social structures, institutional imperatives and cultural factors shape the experience of care at home,” their main function is to relate individual and group experiences with a range of broad social forces to better represent the situation in terms of a relational ethic rather than a static and secluded entity” (pg.171).

Collectivity in this context is a sociological concept directing attention to the potentially crowded nature of the home when it becomes a site of care and more actors from diverse backgrounds become involved. This may act to disrupt the existing social dynamics and ultimately the way such contexts are experienced (Martin-Matthews and Cloutier, 2018; Marshall, Matthews and Rosenthal, 1993). Importantly, as each actor (whether a ‘stranger’ or a ‘familiar’) carries their own cultural/social/political/personal characteristics, collectivity as a relational property implies an extension well beyond the specific dynamics of the caregiver-care recipient relationship, though it does simultaneously frame such a dyadic relationship. The main effect this has is to shift the unit of analysis in the care context beyond the individual in isolation and towards the broader relational context that situates such individuals within their social structures, social systems and cultures (Martin-Matthews and Cloutier, 2018). In the context of home care, collectivity is largely constituted through client and family interpretations of workers as, “adept or inept, [with] their scheduled arrivals as predictable or not,” emphasizing distinctions in the how workers are perceived (Martin-Matthews and Cloutier, 2018, pg. 166).

The collectivity of home care is said to give rise to positive collaboration when complementary care partnerships are formed between formal and informal caregivers. A ‘sharing of care’ results from meaningful and collaborative partnerships between family members and formal care workers, blurring the boundaries between public and private in the home. In this situation family members may provide necessary informational and instrumental support to workers rather than disrupting the care work by adding forms of emotional or instrumental labour.
that may accompany the involvement of family members (Sims-Gould et al., 2015). Indeed, tensions can arise within the collectivity of home due to the diversity and variability of actors. A family’s expectations of workers and their knowledge of clients may not be aligned which can place workers in between family disputes, demands, expectations and conflicts (Rowles and Chaudhury, 2005). Thus, considering the situation as a collective that involves consideration beyond the client-worker interaction elucidates a more nuanced depiction of the forces at work to help understand the experience.

It is not a great leap of faith or logic to link and apply this collective property of home to LTC environments as they include many of the same actors (family, staff, client) but the staff aspect needs to be expanded to include the suite of workers and volunteers that interact with residents and family on a daily basis. Employing this lens by expanding the understanding of each group beyond worker-resident/client dyad in LTC and considering the broader collective properties that shape and reflect their facility-based experiences has great potential to bring about novel depictions of such experiences set within a relational framework. For example, while family members are not residents per se in LTC, they likely play an integral role in the residents and staff experience and as such, should be considered in any approach to care.

Beyond examining the array of interconnected actors in the collective environment of home care, its experience can be framed as a contingency related to three main functions: the Care Plan, home space, and variability of workers (Martin-Matthews and Cloutier, 2018). The care plan is the policies that govern what, how much, and within what time frame services are to be provided by care workers. As a result, what care workers do is partially contingent upon these rules and regulations espoused by governing agencies (Sims-Gould et al., 2015). Tensions arise in this context if/when family members disrupt the labour of the care workers by adding additional tasks beyond what are described in the care plan as, “the boundaries between what families and workers provide are not often as clear as agency policies dictate” (Martin-Matthews and Cloutier, 2018, pg. 169). Alternatively, the care plan can be collaborative when family and care workers
‘share the care’ by working together to accomplish required and/or requested tasks or by creating an environment that lends itself to the other group accomplishing their required tasks (leaving the home/client in a state that is supportive of the care tasks of the other group) (Martin-Matthews, 2007). This situation is mirrored in LTC where basic care tasks are governed by the Ministry of Health and Long-Term Care providing a skeletal care plan and the way that staff carry out these tasks is further governed by the particular facility-based approach to care as well as the information provided by family members. Indeed, the what, how and when of care tasks in LTC can be similarly framed as a relational process when all of these forces are considered rather than simply the worker-resident interaction.

The physical characteristics of the home space play an important role on the experience of care as each household is unique in its ability to support workers undertaking of required tasks. Tensions may arise if the household is unkempt in a way that impedes or adds extra work to a task. The physical layout, sanitation, cleanliness and overall condition of a house all play a role in the experience of care at home while the home space is directly altered as supportive medical apparatus become required (Sims-Gould and Martin-Matthews, 2010). Physical aspects of LTC facilities are of course also related to their experience although the provision of care in LTC is fundamentally different from that of home care environments. LTC facilities are physically diverse and the experience of LTC is also highly contingent on these material particularities which may result in collaborative or contested outcomes for residents, family and staff.

The final contingent property of home care is the diversity and range of skills, capacities, training and schedules of individual care workers (Byrne et al., 2010). Regardless of the care plan or physical environment, some workers possess certain core traits such as empathy and compassion that allow them to form meaningful relationships (which amount to a higher quality of care) more readily than those who do not possess such traits. In LTC, this type of intrinsic capacity is often referred to as having ‘the knack’ for care. This contingency is further intensified by structural features of the labour force such as variability in training, scope of practice and wage equity which
all play a role in worker turnover and familiarity with the requisite care situations and environments (Martin-Matthews, et al., 2013). Since, as Martin-Matthews and Cloutier (2018) tell us, “[care] workers average at least four clients per day, necessitating adaptability in interactions with clients and families,” (p 167) such individual variability in knowledge, capacity and skills plays a key role in the experience in home care.

These characteristics of staff likely also play a key role in the experience of LTC where the espoused facility philosophy either aligns or conflicts with individual staff member approaches, capacities and training. Due to the large and diverse group of staff members required in each LTC facility, it may be worth considering how much of an effect a facility based philosophy/approach such as PCC truly has on individual staff members in light of their own abilities, beliefs and knack for caring. Related to staff characteristics are the rhythms and timings associated with the addition of care to the home environment.

The final relational property to be considered in this framework is the role that *cultural diversity* plays in the experience of care. Rather than focusing, as much research in this vein tends to do, on the immigrant status and/or ethnicity of a low paid and often marginalized work force, the core consideration here is, “how ethno-cultural diversity *between* workers and clients [and families] supports or challenges relational space” (Martin-Matthews and Cloutier, 2018, pg. 171). Recognizing how cultural and gender-based differences between care workers, family and clients/residents impacts the care experience beyond the collective, contingent space provides an even more nuanced lens through which to explain or understand experiences. Such diversity may be experienced as an opportunity for growth where differences are embraced, or conversely as a conflict where hostility is encountered based on deeply held negative racialized beliefs are perceived or through outright discrimination. Some examples cited in the home care context are the preparation on unfamiliar and culturally ‘taboo’ types of food; language and communication barriers; and employment rules banning religious and cultural clothing, all of which might also apply to LTC contexts.
Thinking about LTC in this light, it is clear that cultural differences can play a major role in the experiences of care where for example, facilities may deliver religious services or activities to suit a certain religious or cultural background that can potentially conflict with individual values/beliefs. Indeed, group living arrangements such as LTC can be considered more prone to such cultural conflicts (and collaborations) than the home care context simply arising from the need to consider the values of more individuals and families as they relate to those of the staff and the facility’s strategic planning.

While these potential tensions surrounding cultural differences in LTC are theoretically moving, it is important to note here that this research did not glean any such insights when it came to the particular experiences gathered. This was simply not an aspect of the environment that happened to be eluded to and as such, is a piece of the framework that is not discussed for this inquiry. This does not preclude it as being part of the LTC experience in general but says more about the demographics and values of the particular participants that were involved and possibly about the nature and limitations of the methodological approach. Moving forward it would be interesting to focus on this aspect of the lens in the LTC context however for this inquiry it was the interview responses that drove the analysis and there was simply not enough to warrant the inclusion of this property as an essential piece of the experience.

Beyond the specific proposed linkages suggested throughout this section there are a number of reasons why this framework to understand home care might be extendable to the LTC context particularly for those espousing PCC. First, because when ‘care comes home,’ as discussed earlier, the home itself begins to resemble a LTC facility and is no longer a private space. Second, PCC approaches tend to espouse home-like settings and generally try to replicate an idealized experience of home. It is argued here that an experience of a presumed home-like setting might best be considered through the lens of a framework developed for the home. Considering LTC in this way (through the lens of relational forces that shape experiences of the home) can help to reframe the goals of PCC by eroding the home/institution dichotomy. Finally, the home is a directly
related part of the care constellation for people living in LTC as it is their previous domain. It is typically the main point of comparison for describing experiences in LTC so it is often invoked as a point of tension in contrast with the institutional context.

While the experience of home care may be fundamentally different than that of LTC as noted in Martin-Matthews and Cloutier (2018), it is argued here that such a difference in outcome does not preclude the application of a similar framework and that these two settings are intimately connected conceptually and in practice. Particularly when PCC is the guiding LTC approach and home-like is a stated goal, similar relational forces impact the experience of LTC as that of home care.

3.4 Conceptual contributions to geographical gerontology

The central conceptual contribution that this dissertation makes in the field of geographical gerontology is an advancement of the relational approach to understanding place in the LTC context beyond that of a location. Broadly, this dissertation contributes to the discussions of core geographical tensions about whether place-based ideas should be understood relationally through its relational portrayal of particular experiences of place that have not yet been adequately explored in geographical gerontology. Adopting a relational conceptual lens that was successfully applied to homecare experiences, the landscapes of LTC framework is developed in this dissertation through engagement with the specific LTC experiences it aims to elicit. The specific contribution is to the landscapes of care literature in furthering the idea that where care takes place matters and that places of care are best understood as relational phenomena. The strength of the project’s approach is that it highlights those relational aspects of place that were situated and grounded in its lived experience, building the framework from the ground up and advancing theoretical ideas through engagement with novel empirical findings.

While a relational approach to place is employed in this dissertation, a recent post-phenomenological shift in the social sciences has pointed attention to the pre-conscious aspects of experiences of place. This novel non-representational approach has great potential to enrich
understanding of the unspoken, performed and affective properties of place beyond what is discussed in this dissertation and will be addressed in Chapter Seven as a limitation and suggestions for further research. Interestingly this promising approach shares much with the embodied citizenship critiques from critical gerontology introduced as limitations in the previous chapter, showing another broad interdisciplinary link that might prove helpful in conducting future research that aims to align these fields.
Chapter 4 Research design and methods

“…person-centred is all well and good, but you’ve got to walk the writing on the wall”

I recorded the above quote from a participating facility’s accreditation meeting and specifically from a conversation between a staff member and the accreditor. The exchange was full of platitudes about the merits of PCC as an approach on one side, and the question of what that really means/looks like on the other: a microcosm of the fundamental conceptual discussion (the writing) and a nod to lived experience (the walk) as the methodological object of interest for this project. Perhaps a reinvigoration of how we ‘write’ PCC will better align it with the ability to ‘walk’ it. The tension in this exchange further reflects the underlying conceptual tension between the theory of PCC as a finished project and the reality of its application and experience.

This chapter describes and justifies the methodological structure and processes that were undertaken in this project to uncover the real lived experiences or the ‘walk’ of LTC environments informed by PCC. It is the tensions found in these lived experiences that will ultimately be scrutinized through the conceptual framework outlined in the previous chapter to suggest a novel place-based expansion/continuation of PCC within a landscape of LTC. Thus, the methodological approach that follows generates the building blocks of the core conceptual contribution of this dissertation.

4.1 Theoretical orientation

The goal of presenting particular lived experiences (thoughts, feelings, emotions) of/in environments informed by PCC is addressed in this project through a qualitative methodological approach. The information sought was experiential and intersubjective in nature, implicating the researcher in the findings through a reflexive process of intimately engaging with and making sense of the ‘data’ throughout the inquiry. Elucidating the more foundational components regarding what there is and how we might come to know it, this section describes the theoretical orientation that justifies/necessitates such an approach.
4.1.1 Ontological orientation: the locality of being

Underlying the methodological approach is a humanist place-grounded ontological orientation that is summed up neatly by Casey (2001) noting, “Who we are very much reflects where we are” (pg. 226). Deriving from the phenomenological conceptual approach espoused by early humanistic geographers of the 1970s (particularly, Buttimer, 1976; Buttimer and Seamon, 1980; Ley and Samuels, 1978; Relph, 1976; Tuan, 1976) a ‘locality of being’ framework locates place as a primary ontological structure that incorporates both human experience and the physical/material world in which that experience occurs where to be human is always already to be emplaced (Casey, 2001; Malpas, 2008; Seamon, 2015). The idea that people are necessarily emplaced “presupposes that the very possibility of the appearance of things – of objects, of self, and of other – is possible only within the all-embracing compass of place” (Malpas, 1999, pg. 15). Further, place is not viewed as a strictly physical entity or essentially separate from people’s subjective experience of it, but rather as a complex, generative and dynamic interchange of people-experiencing-place (Malpas, 2001; Seamon, 2015). Indeed, from this perspective, “it is through our engagement with place that our own human being is made real, but it is also through our engagement that place takes on a sense and significance of its own” (Malpas, 2009, pg. 33).

This idea highlights a humanist ontological interchange or ‘inter-animation’ between people and places where lived bodies both belong to and constitute place, while places simultaneously belong to and emerge from lived bodies (Casey, 2009). In essence, place and people are inextricably and ontologically coupled insofar as places make people meaningful and people make place knowable- to be is to be somewhere and what a place is, is bound up with how it is experienced by humans.

As a result, the object of study here is human (lived) experience as it is constituted in and implicates place in its understanding or what might be termed a lived emplacement. Indeed, a lived experience is always already emplaced as a locality of being and as such, provides partial insight as to the nature of that particular emergence of place. Knowledge of this conception of
place is thus similarly of a subjective, partial, particular and emergent nature as it is derived from human consciousness and its intimate relationship to places that make up our everyday individual and social environments (Pocock, 1988; Rodaway, 2015). This focus on subjective, partial lived emplacement is reflected in the corresponding epistemological approach discussed in the next section.

4.1.2 Epistemological orientation: Experiential, empathetic and interpersonal knowing

Personal senses of wonder, humility and reflexivity guide this humanistic orientation to knowledge acquisition. It arises from an intellectual impulse or curiosity towards understanding geographical phenomenon as they are in their own right, bereft of an obligation to appeal to any practical, conceptual or ideological commitments – a way of “seeing that strives to omit nothing yet impose nothing…to see clearly what there is” (Relph, 1981, pg. 177). This disposition amounts to a kind of environmental humility where things in the world (people, places, other living beings) are valued as meaningful just for being what they are. The relationship between researcher and phenomena being studied is founded on an appeal for taking care of things simply because they exist and “in it, there is neither mastery or subservience, but there is responsibility and commitment” (Relph, 1981, pg. 187).

Correspondingly, the study of lived emplacement(s) necessarily implicates the researcher as an integral epistemological medium incorporating a form of self-knowledge or reflexivity—what we study affects us and we affect it as there is no detached/objective position to take on subjective knowledge. As Seamon notes in his (2015) review of humanistic geography, “through studying the lived nature of place…we discover more about ourselves…we perhaps become better human beings because of that understanding” (pg. 45). It is this spirit of wonder, humility and reflexivity that gives rise to the empathetic, experiential and interpersonal modes of understanding that make up the epistemological orientation for this dissertation.

Empathetic and experiential ways of knowing are dependent upon an orientation sensitive to an intimate engagement with or sensing of the phenomenon (Seamon, 2015). The strategy
involve not an objective impartiality to the phenomenon to impose pre-determined theories, but rather a personal participation or engagement with the phenomenon to “find place evocation through facilitating or allowing it to be revealed through the researcher’s own personal engagement” (Rodaway, 2015, pg. 336). Here the researcher strives to authenticate a particular knowledge of place rather than verifying an a priori theory. To do so requires spending time observing and engaging with the phenomenon, suspending/bracketing preconceived notions in an effort to facilitate its ‘speaking itself to us.’ While this project is in essence ultimately ‘testing’ PCC against its lived experience, the initial methodological aspect is oriented towards the gathering of such an experience with no preconceived notions about what may come of it.

Embedded in an intimate and empathetic sensing are principles of respect, patience, listening, observing, reflection and authentication where knowledge is presented as a process founded upon an honest application of these principles interacting with and an ongoing reflection and self-discovery process (Pocock, 1996). An array of methods may be employed stemming from this empathetic and experiential strategy that generally take the forms of observation, contemplation and conversation though it fundamentally features an attitude or approach to evoke a particular sense of place through intimate participation/engagement rather than specific methods.

Coupled with a personal experiential engagement and self-reflection, this study seeks to socially engage with individuals in a form of subjective interpersonal knowing. This requires a participatory epistemological approach to understand the lived experience and emplacement of others as they perceive and live it themselves (Seamon, 1979; Rowles, 1978). The interpersonal research process is essentially an epistemological partnership between the researcher and the subject where, “knowing is emergent and partial subsisting in a relationship between knower and world (objects or beings)…it is lived through conversations, relationships, gestures and actions” (Rodaway, 2015, pg. 338). Paramount to this process are trust and even friendship between researcher and participants where the traditional hierarchy between researcher and participant is
dissolved in favor of a mutually generative approach. In sum, interpersonal knowledge is a subjective, partial and emergent process of coming to know through deep engagement with the research subject(s). Rather than looking for the 'absolute truth', this project aims at producing intersubjective truths that reveal how people make sense of events around them and render them 'true' in their own terms.

Evaluation or ‘authentification’ of this type of knowledge, “ultimately relies upon the quality of the human relationships sustained in the research and the integrity and honesty of the researcher” (Rodaway, 2015, pg. 340). Rather than verification of a causal relationship, authenticity takes the form of intersubjective corroboration where the findings ring true and genuinely move those who participated, other researchers/readers, and to the researcher with a sincere sense of empathy and honesty. To frame an evaluation of authenticity of research describing a particular lived experience, Rodaway (2015) asks, “do the findings or research report move the reader to a kind of emotional engagement with, or wider recognition of, the people, place and experiences revealed, which gives that deeper sense of reality?” (pg.341) Including participants in the research process, presenting the results back to the participating facilities and employing critical and explicit self- reflections throughout the research process (expressed in the discussion and concluding chapters) were some of the methodological steps taken to ensure the authenticity of this project.

4.2 Qualitative research design: A community-based, multi-site case study

This humanistic orientation is enacted through a community-based, multi-site case study design. Broadly, this design denotes a tracing of the qualitatively expressed lived experiences/emplacement of a phenomenon (PCC) across and within research sites in the interest of and in partnership with community stakeholders (mainly the participating facilities). While the case study design/approach has been variously defined, this project adopts Hagan’s (2006) simple depiction as, “in-depth, qualitative studies of one or more illustrative cases” (pg. 240). Case studies allow for a rich and nuanced understanding by employing a variety of qualitative research
methods and concentrating the research on a single phenomenon, individual, organization or community. A ‘thick description’ of the phenomenon of interest is sought through this approach where beyond the immediate behaviors or expressions in which people are engaged, the situational and experiential understandings of those expressions or witnessed behaviours rendering the event or action meaningful are sought and considered (Dawson, 2010). In providing such a thick or rich description of expressed or witnessed behavior/feelings a case study approach can contribute to both the building and testing of theory depending on the specific research goals (Alexander and Bennett, 2005).

For this study, the case is viewed as PCC as a central idea experienced across physical sites and within participant groups. Such an approach examining more than one instrumental instance of a phenomenon is typified as a multiple or collective case-study approach and may be employed to either replicate or contrast situations of interest (Stake, 2005). In this case similarities are aggregated between sites to ultimately generate a interpretation of the lived experience of LTC environments informed by PCC for each participating group. Yin (2003) notes that regardless of the purpose, multi-site case studies such as this compared to individual case studies are, “considered more compelling, and the overall study is therefore regarded as more robust” (pg. 46). To uncover such a thick description of experiences this project employed methods of one-to-one interviews with salient groups and observation periods in each participating facility. The conceptualization and implementation of these methods within a case study approach was undertaken in partnership with the leadership of participating facilities exemplifying a community-based foundation to the design.

Underlying the specific research goals, methodology and dissemination plan was an engagement and direct participation with the leadership of the facilities involved in community-based approach. This approach has been specifically defined by Minkler (2005) as a, “systematic investigation with the participation of those affected by an issue for purposes of education and action or affecting social change” (pg. 113). Moreover, community-based research comes in the
form of a variety of approaches/designs that have as their foundation three interrelated aspects of involving community stakeholders: participation, research, and action. The project actively involves the participating facilities in these three aspects throughout the process where they help to shape the design by making certain methods and participants available, participate directly in the recruitment process and the empirical results will be presented to interested parties in each facility so that they can use the information to improve the quality of care. The project is ultimately aimed at affecting social change through providing the participating facilities with a novel perspective of the experience of their environment that they may use to improve the conditions or justify current practices. My personal dedication to this community-based approach was best exemplified by participating in an accreditation meeting for one participating facility to share with the accrediting body my own experiences in that facility, thus displaying a level of trust that had been built. This research was not merely an academic pursuit but reflects my desire to contribute to a positive change in the community.

4.3 Research sites

The experience of PCC was traced among and within three sites for this project, each one a long-term care facility that espouses their own version of the philosophy/approach but share a PCC foundation (this is inferred from the language in the stated approaches, the provincial guidelines to do so, as well as explicitly stated in the interviews). This section will begin with a discussion of the rationale that informed my choice of facilities with which to partner, including mainly considerations of location -being a community-based project. Following this is a general discussion of how I subsequently gained access and formed research partnerships with the leadership at each research site. Although they are not direct objectives of this project, gaining access to and forming partnerships with the leadership in facilities were the fundamental building blocks to my ability to gather meaningful perspectives. All of the sections following this one hinge on access and partnership, so they are worth careful consideration before moving forward.
Finally, the section provides a description of each facility including their particular espoused approaches to care as stated in their strategic planning.

4.3.1 General location

The consideration of the physical location of the research sites hinged on two main factors: healthcare community and ease of access. This is a community-based project which is reflected in both the practical objective to report the findings back to the participating facilities as well as this methodological consideration of what facilities will be approached to participate. As such, as a first step I elected to contain the search within the boundaries of the South East (SE) Local Health Integration Network (LHIN). Although the LHIN boundaries do not affect where a person in Ontario receives health care services, focusing on one LHIN area ensures that all facilities involved are acting under the same Integrated Health Service Plan (IHSP) which is created to reflect the specific needs of the particular LHIN’s population (Basin and Williams, 2007). The IHSP provides a baseline for comparisons between facilities as well as for eventual communication between participating facilities that wish to share their findings with each other and amongst their care communities.

The boundaries of the SE LHIN are displayed in Figure 4.1 below. These reveal that although the SE LHIN is presented in this project as a singular entity, it contains a range of community types from mid-size urban communities such as Kingston in the south central part of the LHIN to smaller rural communities such as Bancroft in the north western end. While as Herron and Rosenberg (2016) rightly remind us that these rural and small town settings present very different challenges for older adults and their care partners than they might face in more urban areas, this project focused on the finer scale of the particular facilities which all fall under the same governing body, the SE LHIN. Further, a relational understanding of the transactions between the facilities and their surrounding community plays a major role in the eventual results and discussion so these community types are not ignored, but rather addressed from their immediate and historical influence on the particular experience of each facility rather than
beginning from the broader urban/rural discussion. Including the perspective of facilities in a diversity of community types but with the same LHIN agreement might serve to highlight the similarities in some of the challenges they all face, providing them with an opportunity for a meaningful exchange of ideas. Table 4.1 contains the LTC characteristics in the SE LHIN compared to those in all of Ontario. This provides a broad contextual snapshot of LTC attributes in the area of interest and generally locates LTC in the SE LHIN within its provincial context. The 36 LTC facilities formed my initial range of possible research sites. As the scale of the main inquiry is at the individual and facility-wide level, this information is mainly to provide a basic understanding of what is available in terms of LTC. The main thrust of this locational aspect is to provide an initial baseline for communicating and comparing among the facilities.

Not only did focusing on the SE LHIN ensure that the funding opportunities for each facility were aligned, but being based out of Kingston, Ontario this also guaranteed that I could physically access each facility with relative ease. As the project demanded that I spend as much time as possible at each location this was an important practical consideration. Moreover, initial access and partnership with facilities was greatly facilitated by networks in the community as trust is a major factor that initially was granted through networks of existing partnerships in the community. Living in the community of interest was therefore an initial social bridge for access. Having outlined the rationale that allows for exchange of information throughout a community of practice, the next integral step was to access and form partnerships with those who were interested.
Figure 4.1 The Geography of the South East LHIN

http://www.southeastlhin.on.ca/Priorities/Planning/HealthLinks.aspx

Table 4.1 SE LHIN LTC Characteristics Compared to LTC in Ontario

<table>
<thead>
<tr>
<th></th>
<th>SE LHIN</th>
<th>Ontario</th>
</tr>
</thead>
<tbody>
<tr>
<td>LTC Homes</td>
<td>36</td>
<td>626</td>
</tr>
<tr>
<td>Beds</td>
<td>4069</td>
<td>78762</td>
</tr>
<tr>
<td>Avg. Home Size (#Beds)</td>
<td>113</td>
<td>126</td>
</tr>
<tr>
<td>Population 75+ (%)</td>
<td>~11</td>
<td>~8</td>
</tr>
<tr>
<td>2018-2019 Budget from LHIN ($)</td>
<td>189581149</td>
<td>4281473170</td>
</tr>
</tbody>
</table>

Adapted from: Ontario Long Term Care Association (2018)
4.3.2 Access: Forming partnerships through community-based networks

Having outlined the boundaries of my search site and thus the full range of possible facilities with which to partner, I began the process of consulting with my community contacts in Kingston and the surrounding area. This process was in an effort to narrow the search to facilities that I was connected to through a community contact, thus facilitating an initial sense of trust. In my case, the network was based primarily from my role on the Board of Directors at the Alzheimer Society of Kingston Frontenac Lennox and Addington (ASKFLA). My deep involvement with a highly respected organization in the community served to bolster both my direct engagement with people in the LTC field as well as the trust of facility leadership. It was clear from this relationship that my aspirations were not solely housed in academia so there was and continues to be potential for the community to benefit.

Through engagement with a number of board colleagues at ASKFLA who work in LTC and other community contacts I compiled a list of facilities along with the contact information for their Director of Care (DOC). Engaging colleagues to provide this information allowed me to include their names in my initial communication with Facility leadership – an extremely important touch for the first point of contact. In total, I contacted DOCs at 16 facilities via email, each with a message tailored to their particular approach as gathered from their website or SE LHIN description. After initially having received 6 positive responses, three DOCs agreed to a research partnership, granting me access to three facilities for this project. From my perspective as the researcher, these three facilities ultimately came to be included in the research through convenience of location and their agreeing to do so. While the project has its own specific goals and objectives, these were to be aligned with the practical needs of LTC facilities in the community which were defined through my interactions with the facility leadership themselves rather than a priori. The facilities were provided no incentives to be involved in the research beyond their interest in the project as a reflective knowledge-translation exercise that contributes to the community’s capacity to conduct research. As a result, the research partnership agreements
might be better understood as the facilities choosing me and this project, rather than me choosing them. While this self-selection process may have influenced the broad findings as it represents only those facilities whose leadership for their own reasons view this research as important to them, this convenience-based approach allowed me access to the residents, family and staff who were able to speak privately with me to provide open and honest depictions of their experiences. Additionally, while I attended one accreditation meeting for a participating facility, the only other dissemination the facility leadership required was a presentation of the findings back to them. Each partnership officially began with a visit to meet with the DOC to discuss timelines and recruitment along with a brief tour of the facility. I was pleased to have partnered with facilities that each brought distinct physical, social and community-based characteristics as well as forward-thinking leadership that supported my inquiry.

4.3.3 Facility descriptions

Before describing the facilities, I would like to first acknowledge that by simply agreeing to participate in this partially evaluative study, the leadership at each of these facilities have shown a dedication to quality improvement. It is worth noting that I am extremely grateful to have been allowed to conduct research with each facility and humbled by their commitment to the residents. This will be expanded on later in the discussion, but it should also be noted here that regardless of the lived experience outcomes it was clear that each individual in all of these facilities is doing their best to provide quality care. I hope that this academic approach will provide them with new information to help them reframe some of the difficulties they are having.

All three of the participating facilities acknowledged that PCC underlies their approach either through the use of the term ‘resident-centred’ or directly in the interviews when asked to describe their approach. As discussed in Chapter One, facility-based mission statements in LTC in Ontario are required to adhere to the tenets of “resident-centred” care. It is these various forms of PCC that I aim to elucidate to ultimately expand on the fundamental theoretical concept that is
typically used as a synonym for ‘good’ care. Table 4.2 contains the basic characteristics of each facility retrieved from each of their websites and/or the SE LHIN website.

Located on the outskirts of a mid-sized city, Facility 1 (F1) draws mainly from that city while providing a picturesque countryside setting. It is an accredited non-profit care facility, owned and operated municipally that offers 128 beds separated into 4 living areas each with their own dining room including a secure Alzheimer’s unit. Also provided in house are pastoral care, a general store/café, a hairdresser and many personal care options (Nurse Practitioner, 1 Medical Doctor, Physiotherapist). F1 was established in 1968 and was fully redeveloped in 2004 guided by the philosophy of Gentle Care® which continues to permeate the culture of care. With regard to the philosophy/approach to care, this is the only participating facility explicitly espousing a pre-packaged all-encompassing approach (i.e., Gentle Care). The staff and family are all expected to have an understanding of this approach as it is the fundamental force underlying decisions about the social and built environment. With this in mind, it is important to outline a conceptual understanding of Gentle Care to contextualize its lived experience in the next chapter.

An approach coined and conceptualized by Moyra Jones in her (1996) book, Gentle Care is a ‘prosthetic’ model of dementia care. It is grounded in the principle of accurately defining the deficit the individual person is experiencing, and organizing the macro-environment, people, programs and physical space, into a prosthesis to compensate for the deficits in functioning, to support existing or residual function and to maximize the quality of life (Vitali, 2004; Jones, 1996). Simply put this approach considers how the built and social aspects of the environment can be organized and manipulated to enhance individual continuing capacities rather than only managing and tending to the disease states. Since the disease is a chronic one, the focus moves away from the biomedically informed symptom-relief via drugs and technology, towards an emphasis on inherent human value and connection to locate and support remaining functions (Jones, 1996). This is synthesized in F1’s strategic planning as resident-focused care which empowers residents to make individual choices. This alignment with PCC is further emphasized
from the following quote from a staff member at F1: “Gentle Care kind of takes Person-Centred care to the next level by letting them go sort of on their own time-tables. It’s really from person-centred care.”

Although there is no explicit reference to PCC in Gentle Care (though ‘resident-focused’ might be viewed as synonymous), it is quite clearly an approach that derives directly from Kitwood’s (1997) initial formulation. At best it is a faintly more practically presented version of PCC, as aside from the semantic changes (i.e., from ‘dialectic’ to ‘prosthetic’) it is grounded in the same philosophical tenets and reflects PCC’s initial move away from a biomedical approach.

Facility 2 (F2) is located in a mid-sized city, adjacent to the city’s major hospital and other healthcare services. An accredited, non-profit facility that is operated municipally, it is the largest of the three facilities containing 168 beds separated into 6 ‘Resident Home Areas’ sharing 3 dining areas and each containing their own Family dining room for groups of up to eight to book at their leisure. Located onsite are a hairdressing salon/barber shop, Village Shoppe, and chapel. Dental care, hearing tests, eye exams and foot care are also provided onsite. F2, in its current state, was established in 2005 after a minor (across the street) relocation and subsequent rebuilding of the facility, a visual upgrade but point of contention in terms of lived experience. Guided by the catchphrase ‘it feels like home’ and the mission statement of providing ‘supportive long-term care in a home-like atmosphere, promoting comfort and contentment, while respecting dignity and identity’ the rebuilt facility focuses on all aspects of what it means to be ‘home.’ In subsequent chapters, the attempts at ‘home-creation’ will be prodded further but for now it is adequate to say that the approach to care and subsequent built environment is heavily based on conceptions of home in F2.

The philosophy of care in this facility is expressed as a fleshed-out list of tenets/beliefs (Figure 4.2 below) in contrast to F1’s packaged approach. This is a lengthy and encompassing list, making it more difficult to refer to in the moment or elaborate on when questioned about the philosophy but it provides an adequate snapshot of how the facility aspires to operate and what is
valued. Further, and to align the approach with PCC, a staff member noted about the particular approach in F2 that “I think at its most basic level it’s person or resident-centred care so that everything we’re doing relates back to a person-centred approach.”

**Figure 4.2 F2’s philosophy of care tenets**

<table>
<thead>
<tr>
<th>We believe that each resident is a unique individual who experiences his/her surroundings in a different way.</th>
</tr>
</thead>
<tbody>
<tr>
<td>We believe that each resident must have a sense of personal worth and importance as an individual and that all staff must endeavour to ensure the physical, social, psychological and spiritual needs of our residents.</td>
</tr>
<tr>
<td>We believe that each resident must be allowed to maintain his/her personal dignity and must be treated with courtesy and respect.</td>
</tr>
<tr>
<td>We believe that the resident’s family is an integral part of the resident’s life and interaction between staff, family and residents should be encouraged.</td>
</tr>
<tr>
<td>We believe that each resident should be encouraged to maintain his/her personal independence as much as possible and that physical and psychological support must be offered to help the resident achieve his/her full potential.</td>
</tr>
<tr>
<td>We believe in providing residents with a safe and clean environment.</td>
</tr>
<tr>
<td>We believe in preparing and serving nutritious and appetizing food to residents of the Home.</td>
</tr>
<tr>
<td>We believe that we should participate in the development of community outreach programs, to assist the elderly population to remain in their own place of independent living as long as possible.</td>
</tr>
<tr>
<td>We believe that the staff should be familiar with and carry out the philosophy and policies of the Home.</td>
</tr>
<tr>
<td>We believe that the staff should be encouraged to develop personally and professionally, thus fostering pride and personal satisfaction, a sense of responsibility to work and loyalty within the Home.</td>
</tr>
<tr>
<td>We recognize the valuable contribution of family, staff, volunteers and Auxiliary, to improving residents’ quality of life and assisting in achieving the Home’s mission.</td>
</tr>
</tbody>
</table>

Facility 3 (F3) is the smallest of the three facilities with 75 beds and no Dementia-Specific area. It is also the only one of the three that was not purpose-built as an LTC facility, so the basic layout and design features are the most distinct of the three. Most noticeable is the lack of clusters of rooms into smaller nodes forming their own ‘communities’ as the other facilities
have. Here the only division is the two floors so there is much more intermingling between residents and staff on a daily basis than in the other facilities. Additionally, this is a for-profit facility operated by a private company (rather than municipally), though their funding still comes from the LHIN so they are essentially running under the same service agreement as the other two facilities.

F3 is accredited and offering amenities such as a hair salon, tuck shop and library. It is located in the heart of a rural village and boasts a strong connection to the community as the main selling point. On paper (or on ‘the walls’ to continue with the opening quote) the philosophy of care at F3 is not as fleshed out as the other facilities. Claiming only to ‘provide exceptional care and services in a home-like setting’ in a facility that is described as a ‘home away from home’ in a ‘little village with a big heart’ which is a representative description of the facility itself. In terms of a particular care philosophy F3 espouses ‘Resident Centred Care’, again reflecting a PCC foundation. Again the staff members interviewed in this facility explicitly aligned the approach to that of PCC through statements such as “The approach here would be Person-Centred, we are here for the residents and we work where they live.”

Table 4.2 Summary of facility characteristics

<table>
<thead>
<tr>
<th>Facility</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beds</td>
<td>128</td>
<td>168</td>
<td>75</td>
</tr>
<tr>
<td>Secure Dementia Unit?</td>
<td>YES</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Philosophy of Care</td>
<td>Resident- Centred; Gentle Care ®</td>
<td>Tenets: Home-like, Supportive, Comfort, Contentment, Dignity, Identity</td>
<td>Resident-Centred; “Home away from home”</td>
</tr>
<tr>
<td>Surrounding Community Type</td>
<td>Outskirts of Mid-Size City/Rural</td>
<td>Mid-Size City</td>
<td>Rural farming area</td>
</tr>
<tr>
<td>Staff/Resident Ratio</td>
<td>1:8 Day; 1:10 Night</td>
<td>1:17</td>
<td>Unavailable</td>
</tr>
</tbody>
</table>

While these facilities differ in many ways, they share a PCC based approach as shown in their strategic planning as well as directly stated in the research encounters. Moreover, the methodological goal of this project is to trace the lived experience(s) of PCC rather than
critiquing individual people or facilities. As such, the discussion combines participant groups
from each facility to focus on experiences of the approach for each group in general rather than
the particular facility. Correspondingly, the research methods conducted in each facility diverged
less so than between groups and the rest of this chapter reflects that by focusing on the research
process for the participating groups (residents, staff, family) rather than the specific facilities.

4.5 Ethical considerations

Beyond the institutional ethical requirements for conducting research with humans, the
main ethical considerations for this project were obtaining informed consent/assent particularly
for the resident group and maintaining confidentiality, defined as, “an active attempt to remove
from the research records any element that might indicate the subjects’ identities” (Berg, 2009,
pg. 90). To ensure confidentiality in the dissemination, all participants are represented as a
member of their participant group to obscure their identity and specific role in the facility.
Quotations used in the write-up were carefully considered in terms of their ability to be traced
back to individuals as there is a minor risk for staff members being identified as being critical of
the facilities approach, while family and residents are faced with even less risks if identified. As
noted earlier, to further obscure individual sources of statements the quotes used in Chapter Six
represent an amalgamation or aggregation of facility experiences between groups. Further,
specific staff roles are not highlighted which could potentially lead to a breach of confidentiality.
An intimate research partnership with management at each facility ensured that no boundaries
would be crossed and that all individual participants were confident that the project was
supported internally. As a result of this level of trust and oversight, while measures were taken to
ensure confidentiality the professional and personal risks were minimal for participants.

Consent on the facility level was sought through engaging with leadership to build trust
in the project and myself that would lead to an acknowledgment in the form of written voluntary
consent before the research began. Each facility had a slightly different process, but they all
amounted to internal written consent that bolstered my institutional ethics application and ensured
that the management at each site was comfortable with the project and methods involved. Individually, voluntary informed consent was sought from every participant immediately before each interview based on their understanding of the goals of the project and willingness to participate. These forms are the only medium that contains participant names and will be destroyed within 3 months of project completion. For the resident group who potentially were living with a form of dementia, beyond the written informed consent, assent was sought throughout the interview process to ensure their continued situational capacity and willingness to participate. Proxy consent was not required as while there were staff and family members form the Alzheimer’s-specific areas, no residents in these areas were to be interviewed. This approach is expanded upon in the following section but fundamentally it denotes an affirmation of the continued capacity and personhood of the participant more so than the alternative of seeking indirect consent from a healthcare representative.

4.6 Research methods

Having acquired ethics approval from the General Research Ethics Board (Appendix I) along with internal approval from the administration at each participating facility, semi-structured interviews were conducted with staff, family members and residents in each facility that were provided context and perspective through overt complete observation periods at each facility.

4.6.1 Semi-structured interviews

In total 55 semi-structured, in-depth interviews were conducted with staff, family members and residents at the three participating facilities. Semi-structured interviews allow for the implementation of a number of pre-determined questions to be asked in a consistent order. However, interviewers are permitted the freedom to digress and probe further based on the nature of each specific encounter (Berg, 2009). This was the preferred approach as it empowers the participants to describe their own experiences and feelings while giving them broad structures in which to do so. Within broad pre-determined questions about general lived experiences, probes were used to either direct participants to specific aspects of their experience or to simply
encourage further elaboration of the current line of conversation. In this sense, the interviews were informal and conversation-like, playing out as organically as possible to facilitate an exchange of information that was as honest and unburdened by professionalism as possible.

While the specific language of the pre-determined questions differed among groups, the primary ‘lived experience of PCC’-framed inquiry was present in all groups. The sampling strategy employed was purposive among groups and based on convenience within groups. To expand on this, the sampling approach required recruitment of members of each group; however, the specific amount from each group was based on quality and interest rather than an arbitrary number of participants. Recruitment methods differed slightly among groups in a manner discussed below.

The interviews were undertaken concurrently at each facility in the span of one year and resulted from a number of recruitment methods that were tailored to each group and facility based on information gathered from research partnerships with the DOCs. Again, the quantity of interviews was a secondary consideration to quality in terms of depth of experiential information; however, this total amount was found to be satisfactory particularly considering the time constraints of the project. Each group is represented in a meaningful way in each facility in terms of quality and quantity and due to the partnership with the DOCs everyone who was interested in participating was given an opportunity to do so. All of the interviews were recorded and subsequently transcribed using transcription software. These transcriptions were stored on my computer and backed up to an external hard drive for further analysis. They will be destroyed within three months of project completion.

Although there is much overlap between the participant groups in terms of the particular interview process undertaken, there are enough significant differences to warrant a separate description of the specific process for each group. This process broadly includes defining/justifying groups involvement, recruitment, interview setting/timing, tailored interview questions for each group, and specific group-based considerations for the interview approach particularly for residents who were living with a dementia. Differences between participant
groups in these aspects of the process will be highlighted to display a sensitivity to and
accounting for the differences among participants themselves.

4.6.1.1 Staff

The Staff group was defined simply as anyone who works full-time in the participating
facilities. While there are many different roles that staff members play in LTC, everybody is
expected to behave in accordance with the facility-wide PCC approach espoused. Indeed, the
experiences of all staff members, regardless of their specific role, are equally embedded in the
care approach and, as such, I embraced this plurality of experiences by seeking out a wide range
of types of staff members including, managers, direct care, environmental services and
administrative services.

In total, I conducted 22 interviews with staff members that were relatively equally spread
out amongst the three facilities. Recruitment for this group was largely accomplished directly
through the DOCs who provided time and space in each facility to conduct the interviews after
sending out requests either via email or in person. This direct approach was helpful to locate
specific staff members ensuring an engagement with a wide array of roles within each facility
providing a range of experiences with the care philosophy. Recruitment posters in each facility
yielded a small amount of interest from staff members along with engagement with them during
observation periods while the vast majority were recruited by DOCs based on discussions we had
had regarding targeting specific roles. On that point, while the specific roles are not highlighted in
the findings due to anonymity consideration, there was an attempt to garner the perspective of a
broad range of roles within each facility. The DOC in each facility and I compiled a list of sought
after roles and requests were sent directly to those staff members by the DOCs to possible
participants including the space and time they would be allotted during their work hours to
participate. Written consent was provided at the beginning of each interview following a debrief
about the purpose of the project (Appendix II).
The interview guide (Appendix IV) for this group includes three foundational questions and a number of prompts to guide specific conversation threads. The three main questions are: ‘what is your understanding of the approach’, ‘how is it reflected in your everyday experiences here’ and ‘what are the challenges associated with this approach?’ Specific prompts to help guide the conversation to address physical and social aspects of the experience, individual versus group philosophies and specific traits that best support the approach. These interviews all took place in the facilities and ranged from 20-40 minutes in length. As this group had the most experience engaging directly with the care approach these interviews yielded much insight about their particular everyday transactions with the environments informed by them and with little prompts needed.

The primary limitation for this group was derived from the recruitment methods which largely were undertaken by the DOCs. This approach, while proving to be effective in terms of general recruitment, does allow for potential institutional bias where staff could be handpicked based on a positive perspective of the approach. Additionally, being recruited directly by the DOC may have placed undue institutional pressure on staff to participate and to be weary of their management’s involvement thus affecting what they share. To mitigate against this influence, I assured participants that I am the only one with access to the research materials and that they would remain anonymous. Additionally, the DOCs at each facility were supportive of the research, particularly where they could receive feedback about tensions in the experience of the environment to facilitate improvements in the quality of life for everyone involved. Based on their instrumental participation and willingness to hear critical perspectives to ultimately improve the care approach, it is unlikely that they had an incentive to influence the recruitment or interview process in any way.

4.6.1.2 Family

The Family group consists of family members of residents in each facility. This is an important perspective as they typically have been the informal caregivers for their loved one and
are a personal connection between staff and residents. Family members are intimately involved in choosing the LTC facility that their loved one moves to and often (though variably) spend a great deal of time in the facility visiting their loved one and interacting with staff to mediate the experience for residents. Additionally, their perspective is less likely to be tempered by institutional allegiances providing assurance that it is more likely to be open and honest. Family members were less likely then staff members to recite facility-based rhetoric in their explanations of the experience of the care approach. Thus, they often elucidated a more personal depiction of the experience without the need for prompting by the researcher.

In total, 18 family members were interviewed with an even split amongst the three facilities. Recruitment for this was accomplished in three ways: posters displayed in each facility garnered some interest particularly towards the end of the collection period (Appendix V), a presentation of the research at family council meetings in each facility brought about the majority of participants, and direct participation requests from DOCs in each facility to those family members who they have formed relationships with rounded out the recruitment processes. Contrary to the staff group where the DOCs provided space and time in their participation request, with this group the DOCs contacted family members directly to simply notify them of the project and to provide them with my contact information. Introductory presentations at family council meetings were particularly fruitful recruitment efforts as they gave me an opportunity to explain the benefits and goals of the project directly to the group as well as fielding any questions or concerns that they might have. Written consent was granted in person immediately before each interview following a reminder of the goals and purpose of the study.

Interviews with this group took place in many different settings based on convenience for the participants. A number of the interviews took place in the facility of interest during the family member’s visiting time with their loved one and often these were done with the resident present. Even more took place in the community or in their homes. Interview length ranged from 20-40 minutes. The core questions asked from the interviews guide (Appendix IV) were: ‘what is your
understanding of the approach to care in this facility,’ ‘how does this approach play out in your experiences,’ and ‘what tensions do you experience/what are the challenges you face in light of the approach?’ Again, specific prompts were used to direct participants to refer to the social and physical aspects of the environment in their explanation of their experiences. I found the experiences of this group to be highly variable and largely based on the amount of time spent visiting and/or participating in the care of their family member.

The recruitment approach led to a potential bias towards only including those family members who are highly involved in the care of their loved one, particularly through family council meeting recruitment. Additionally, those family members recruited by DOCs could have a positive bias or feel pressure to frame their experiences in a positive light. While I acknowledge these potential biases, the family participants, being active in the facility and in the care of their loved one, had vast direct experience in each facility but were more intimately concerned with the quality of life for their loved one. Family members who do not often visit would not have been able to share as lucid or representative experiences in the facility. They would not have engaged with the philosophy or seen first-hand how the staff interact with the residents. As a result, while these perspectives may not be as critical as those from less involved family members, they are more likely to be informed and nuanced simply due to an increased engagement with the environment.

4.6.1.3 Residents

Although this project did not target specific resident characteristics, it is imperative to keep in mind that a high percentage of residents in LTC are living with a type of dementia (64%) and that these residents are often denied a voice in their own representation. As a result, I approached the research with this group as if all participants would be living with dementia, making sure to include all interested residents regardless of their cognitive abilities or diagnosis. That is to say that while I did not directly ask the residents about their health status (residents are people beyond their specific diagnosis), I brought a sensitivity and empathy to each interaction
that kept me aware of any agitation or discomfort caused by the research process. Additionally, I prepared to remain flexible in my communication with the residents as one would when interacting with someone living with dementia. These traits are required to engage with anyone however are magnified when interacting with people living with dementia. As such, this was my focus to make sure that all of the residents who wished to be interviewed could do so comfortably. Indeed, this research was done with rather than on people living with dementia and a number of resident participants did note (or a staff member/family member noted) that they were living with dementia before or during the interview encounter (however this was unsolicited). To account for this important perspective and before describing the interview process, below I provide an explanation for why and how I involved people living with dementia in the research process beyond my interest in their experiences.

Keady, Nolan and Gilliard (1995) argue that, “if we are to achieve the ideal of responsive, flexible, individually-based services for people with dementia, we must listen carefully to their experiences and their opinions” (p. 15). This brings up the question that if people with dementia are, indeed, able to reflect on their experiences and their views on the services they receive, then why does the idea of hearing the views of people with dementia still seem so novel (Goldsmith, 2002)? Broadly, as Wiersma (2008) notes, “assuming people with dementia cannot participate in research or are unable to share views and experiences is a reinforcement of negative stereotypes of incapacity” (p. 10). Similarly, it is argued that prevailing negative perceptions of people with dementia create an inherent power inequity in society that can be shifted through the inclusion of individuals with dementia in research (Wilkinson, 2002).

Three main considerations surround the question of how to involve individuals with dementia in the research process: consent, interviewability, and understanding. Beyond seeking consent prior to the interview, it is imperative to gauge assent throughout the process as the memory of consenting to the meeting may not be clear. Assent is defined as a willingness to participate in the research task presently being undertaken (McKeown et al., 2010). In seeking
assent during each research encounter, the process of consent remains sensitive to what the individual with dementia is specifically asked to do, and attention remains focused on the individual and their present feelings. Consent or assent from people living with dementia must be viewed as an ongoing process, rather than an *a priori*, static event (Hubbard et al., 2002). This is a result of the fluctuating nature of the way dementia impacts an individual's cognitive abilities over time that may render an individual's ability to provide consent or assent different throughout any given day and between days (McKeown, et al., 2010, Hubbard et al., 2002).

Central to research that includes the participation of individuals with moderate to severe dementia is determining which individuals are (or are not) *interviewable*. In the past, researchers have employed cognitive tests such as the Mini Mental Status Examination (MMSE) to determine the ability of individuals with dementia to communicate their views, feelings, and experiences, though there is much debate about their correlation (Cowdell, 2006). In fact, Fisk and Wigley (2000) contend that there is little evidence to support a relationship between MMSE and research performance. Moreover, Fisk and Wigley (2000) viewed the exclusion of individuals who might have failed a cognitive test as inappropriate and note that the administration of such an instrument may induce anxiety and agitation. Instead of relying on clinical indicators such as the MMSE to determine interviewability in their study exploring care quality and involving residents in a 'care home', Fisk and Wigley (2000) developed a series of questions asked at the beginning of each interview to determine which individuals would be able to give reasoned responses to the interview questions. Similarly, in their ethnographic study of quality of life in institutional care settings, Hubbard et al. (2003) ascertained interviewability by spending thirty minutes attempting to converse with possible participants. Rather than applying a universal indicator, these approaches acknowledge the inherent variation in the disease trajectory of dementia between individuals by determining interviewability based on situational capacity. This is consistent with the tenets of PCC as individuals with dementia are not simply being grouped together based on a similar diagnosis or score on a universally administered instrument.
The main difficulty for understanding lies in how the researcher must find meaning through conversations that are not necessarily reflective of everyday speech patterns. Goldsmith (2002) explores the area of communication with people with dementia by asking, “to what extent is it possible to communicate with people with dementia?” (p.5) Problems of communication arise for both the researcher and the person with dementia, and we may not yet have the language to describe the experience. For Goldsmith, expectations of how a 'normal' conversation or social interaction should play out need to be dropped. This allows for the researcher to be creative, flexible and open minded throughout the interaction and thus allows for new meanings to emerge. Goldsmith (2002) echoes Kitwood’s (1997) idea that when engaging with people with dementia. We are drawn into a world in which we recognize the limits of our own power and cognitive capability as much as the limitations and capacities of the individual being observed or interviewed. We are required to face up to parts of ourselves that we often prefer to remain concealed such as the extent to which problems of communication lie in us rather than in the person with dementia and how our mindset and worldview affects the communicative relationship (Goldsmith, 2002). In this sense, engaging with people with dementia is as much a look inward as it is a study of their experience.

With these considerations of assent, situational capacity, and reflexivity in mind and applying them to the interviews with this group, I was able to directly involve all interested residents in the research process and create a discursive space for their voices to be heard in their own representations of their experiences of PCC informed environments. In total, 15 residents were interviewed, evenly spread between the three facilities. Recruitment for this group was accomplished through introductory presentations at resident-council meetings, direct engagement during observation periods as well as suggestions from DOCs based on their knowledge of the residents. All resident participants consented directly for themselves providing written consent before each interview (form displayed in Appendix III) and informal assent was sought.
throughout each interview either through a direct question of whether they would like to continue speaking with me or through a judgement based on behavior implying agitation or fatigue.

The interview guide for this group (Appendix IV) contained four simple questions: ‘what do you like/dislike about living here’; ‘where do you spend most of your time and why’; ‘who are your friends here and who do you spend most of your time with; and ‘what would you think would make this a better place to live?’ The varying level of cognitive capacity of residents interviewed required a range of interpersonal approaches based on my situational awareness of each individual encounter. The interviews took place in the residents’ rooms as well as in various locations throughout each facility where the resident felt most comfortable or happened to be in that moment. The length of these interviews ranged from 10-30 minutes as some were cut short due to agitation or fatigue on the part of the resident.

A reflexive approach led me to realize my own shortcomings as an interviewer due to a lack of experience communicating with people living with dementia and mainly with my lack of knowledge about individual residents being interviewed. The main limitation with this group was this lack of communication experience and personal relationship which may have stunted some otherwise fruitful conversations. In that sense, the challenges with this group were internal ones. The research could have benefited from building meaningful relationships with fewer residents throughout a number of meetings rather than a single interaction with each. Most of the interviews with this group yielded a wealth of experiential information and my comfort and ability to engage meaningfully rose with each encounter.

4.6.2 Observation as a mode of study

While the interviews served to access the subjective lived experiences of the research participants, an observation phase in each facility was employed to ultimately provide context in the form of my own personal experience of day-to-day life in environments informed by PCC. A residual benefit of the observation phase was to passively recruit interview participants from all groups, though this was not actively sought. In total, I spent approximately 35 hours in an
observational capacity spread out relatively evenly among the facilities. Typically, these encounters consisted of 1-2 hour visits at a time where I took the form of an overt complete observer or, more commonly, a ‘fly on the wall’ (Berg, 2009; Denzin and Lincoln, 2005). Pre-arranged and scheduled through engagement with the DOCs, these observation encounters took place in many different areas of each facility as well as within at least one activity session in each facility, giving me opportunities to witness interactions among all groups of interest. Although I did participate in some of the activities, it was known that I was there mainly in a research capacity. Time was spent in nursing stations, interacting with residents, and generally in various areas of each facility. As a ‘fly on the wall,’ during these visits I focused on simply taking in the people and environment as they interacted in their everyday manner so I might be able to better situate the experiences described in the interview process. These are not directly addressed as findings but played a contextual role to situate the findings in my experiences in each facility.

The challenges associated with this method were both practical and conceptual. In practice, I was limited in my ability to physically access each facility due to limited resources and time. Conceptually, I would have benefitted from visiting at a wider temporal range at each facility. For example, I was not able to observe a nightshift, and this is an integral aspect of the lived experience that many staff members referred to in the interviews. Additionally, while it was known that I was there as a researcher, my presence did seem to be disruptive for staff at times as they were confused as to what level of inclusion to grant me. Indeed, some staff members were understandably suspicious of my presence which likely affected how they presented themselves. Overall this observation phase was an integral part of my understanding of the experience of environments informed by PCC. It provided me with the necessary context to better understand and situate participant experiences as well as largely constituting my own.
4.7 Content analysis: Distilling a lived experience

In general, content analysis is an in depth, thorough and systematic consideration and interpretation of a collection of raw data with the goal of identifying patterns, themes and meanings (Berg and Latin, 2008; Leedy and Ormrod, 2005; Neuendorf, 2002). My goal in using content analysis was to refine the interview responses to generate an experiential account of the lived experience of environments informed by PCC. This was accomplished through both inductive and deductive reasoning processes. Common themes within groups emerging from the responses (inductive) were set/categorized within an ideologically relevant conceptual framework (deductive) to express the results as direct responses from participants. The responses are, however, organized within a meaningful and discipline-specific structure for further refinement based on specific research goals.

The specific analytic approach for this project was largely in line with Berg’s (2009) seven stage model of a qualitative content analysis process and as such it is a helpful explanatory tool in reference to which I will present my particular approach to making sense of the raw data. Berg’s adapted process is as follows:

1. Identify research goal
2. Determine analytic categories (from the salient literature and connected to the research question)
3. Read through raw data and establish emergent themes
4. Determine criteria for sorting raw data into categories
5. Sort the data into categories
6. Review textual materials as sorted into categories seeking patterns of understanding
7. Consider the patterns in light of relevant theory/literature and relate analysis to extant literature to offer explanations in reference to research goals

The research goal for this project was to gain insight into the lived experience (the walk) of LTC environments informed by PCC. The analysis that follows, founded on the assumptions
inherent in the humanist philosophical orientation of my research, speaks to this goal. For the second step, the analytic categories/framework function was to connect the emergent themes with theory and existing literature in two of the core disciplinary fields for this project: dementia care and geographical gerontology. Here, an artificial separation of place aspects (physical and social) which are intimately tied to experience from a humanist perspective are aligned with Kitwood’s dialectic (neurological and social) conception of the experience of dementia to broadly categorize emergent themes into their social and physical manifestations. This is not an aspect of PCC that has been critiqued and, as such, it is generally accepted that there are social and physical aspects to the experience of dementia, or any experience for that matter. Additionally, since it has been ontologically assumed that experience is place-based and place has been imagined in geography to have both physical and social aspects, it follows that this inquiry situates the subjects’ stated experiences within a broad framework of place. It is worth noting that this is one of many ways this project seeks to align the core disciplines or at least to highlight conceptual commonalities. That is, a geographic perspective is suggested throughout this inquiry as a way to bridge disciplinary boundaries through the co-creation of the concepts of place and experience/identity. The analytical categories are derived from both the dialectic framework of Kitwood describing the experience of living with dementia and the relational version of place from geographical gerontology. While both view these dimensions of place/experience as acting simultaneously in reality, this artificial separation allows for a more pointed and nuanced position where certain aspects of the experience can be magnified conceptually as the analysis progresses.

Regarding step three, within the broad physical and social categories, themes were then drawn out of the interview responses based on an intersubjective understanding of the responses gauged from the interview transcripts. This inductive process was driven by the words and phrases used by participants to describe their experiences. Direct quotes from participants defined the themes but my interpretations ultimately justified the emergence of themes and the allocation of statements into each theme. In other words, the criteria for highlighting themes and sorting
statements into themes was based on my interpretation of the meaning of direct statements founded on an intersubjective understanding derived form the research process.

The text or ‘data’ in the form of representative quotations from the interviews was then sorted into emergent thematic categories as well as broad analytic categories by simply creating a new document to re-present them as such (steps 4 and 5, respectively). In this thematically categorized format, the text was again reviewed following step 6 but in a search for a holistic understanding (rather than patterns) within participant groups. At this thematic level is where the practical goal of the research was satisfied, as it presented a picture of the lived experiences in each facility in a format that is easily digestible and applicable to the reality of everyday life for those involved. A relatively straightforward presentation of the findings, unobscured by ideological, theoretical or conceptual frameworks but structured in a meaningful way is an ideal format in which to present the data back to the participating facilities. This provided them with a new perspective about how their approach to care was being applied and experienced and represents a core aspect of the community-based approach to this project. The thematically arranged direct statements along with corresponding statements about tensions related to a theme were presented to highlight places for considering improvements as well as current successes.

The academic analysis proceeded beyond the practical obligations by relating the results (particularly the previously mentioned tensions) to the extant and salient literature as depicted in the 7th and final step for this analysis process. This is displayed in Chapter Six where the relational framework outlined in the previous chapter from geographical gerontology is applied to further refine the analysis through a particular disciplinary lens. Specifically, the experiential tensions found in the initial content review (Steps 1-5) are considered as gaps in the application of PCC and as such, conceptual spaces for refinement of the PCC theory/approach. It is through this consideration that the conceptual research goals are addressed, expanding PCC through a geographical framework and, in doing so, aligning and contributing to these seemingly disparate
disciplines in their understanding of how older adults relate to their environment in the LTC context.

In sum, while the following chapter displays the empirical findings thematically arranged within a broadly dialectic framework in a way that helps present these findings back to each facility, Chapter Six extends the analysis to focus on the tensions found in the experiences of PCC. These are ultimately framed within and in support of the construction of landscapes of LTC structure to address the conceptual goal of expanding and ultimately ‘placing’ experiences of LTC informed by PCC.
Chapter 5 Presenting the lived experiences of long-term care environments informed by person-centred care

“Long-Term Care philosophy is not rocket science. All you want is for staff to love your family member.” (Family)

The above quote from a family member who participated in the research is both representative of and undermining to the objective of this inquiry. It undermines the idea that any informed best-practice above a loving relationship is required to provide an adequate level of care but also it speaks to the importance of the main objective of this chapter to trace the lived experience of individuals providing LTC. If a loving relationship is the goal and we know that PCC has not quite lived up to its promise and we assume that staff are trying their best, what are the practical issues in implementing PCC that led to a situation where there is a real or perceived lack of ‘love’ in the care environment? This chapter focuses on the residents, staff and families’ lived experience in each facility that can bring some nuance to our understanding of their individual and group agreements and tensions with person-centred approaches espoused. This nuanced and fine-scaled approach brings attention to particular challenges and realities that participants face in their everyday experiences of PCC and the environments that amount from its implementation in LTC. Although it is not “rocket science” LTC involves a complex array of relationships and physical care needs to constantly manage and foster loving relationships. PCC requires careful consideration of the physical and social-psychological aspects of places in terms of how they are experienced by their diverse and often vulnerable occupants.

The two goals of this chapter are to present the empirical findings from interviews with participating groups in each of the three facilities and to highlight tensions within groups and facilities to be analysed in subsequent chapters as possible ways that core concepts in geography can contribute to PCC. Further, in presenting the empirical findings for these groups, this chapter satisfies the community-based objective in providing practical feedback to each participating facility about how their particular approach to care is experienced by those who live, work and visit regularly for them to use as they see fit.
It is important to mention at this point that the individuals working in each facility are doing their best within potentially difficult circumstances and any critique levelled is of the approach itself, not the individuals sharing information. Experiences were generally positive in all facilities and they all are worthy of great praise. Keeping in mind that for many staff members at each facility “long term care is over regulated, over scrutinized and under resourced,” it is imperative that we learn from these particular experiences to make the best of the resources available as well as justifying the allocation of additional resources through this and similar research.

5.1 Structure

The structure of this chapter highlights the three major themes that emerged from a content analysis of the interviews within each group and each facility: flexibility, atmosphere and relationships. These themes encapsulate the aspects of the lived experience that were generally agreed upon by all groups considered in this chapter and provide an internal structure for the portrayal of their experience. There is much overlap in terms of where participants in each facility expressed agreement about their experience of these themes as they all align well with PCC (the general approach espoused in all facilities); however, certain aspects are emphasized and experienced in subtly different ways among facilities amounting to particular internal tensions. Instead of pre-defining the themes their definitions will emerge through the quotes presented from participants in this section.

Following the conceptual foundations of PCC, Kitwood’s (1990;1997; and see Chapter Two) dialectic approach provides a framework for presenting these themes in terms of how they are shown in both the physical and social-psychological aspects of experience. Through this lens we can trace the experience of PCC from the way it was initially formulated and interrogate it through its own way of approaching the world. Each emergent theme will first be discussed in terms of its social-psychological and physical contribution to the lived experience for each group and in each facility. While in reality these aspects exist simultaneously to elucidate an experience
of place, this artificial separation allows for a finer and more nuanced understanding of the situation to pinpoint particular areas that require practical and/or theoretical attention. Following this analysis will be a discussion of the tensions that arose within each facility. Tensions arose both between and within groups and facilities either based on competing experiences within a facility or competing values/resources among facilities. These provide points of emphasis for facilities to consider addressing or simply to better understand different perspectives of the lived experience of their care approach.

5.2 Presenting lived experiences of PCC

The remainder of this chapter presents the participating groups’ lived experience of environments informed by PCC. Each of the three themes is presented through one or more representative quotes from participants in terms of its social-psychological and physical manifestation for each facility. These are further separated into specific participant groups to present three similar but subtly distinct versions of how PCC is experienced and where tensions exist. Notably, the resident interviews from F3 are not included as they were not robust or intelligible upon analysis. While I was open to interviewing all interested residents, I was limited by the time available to conduct further rounds of recruitment and it was simply unfortunate that those who did participate in this facility were difficult for me to make sense of given the time restraints (I would have liked to return and spend time with the residents in a less stressful interaction). The lack of F3 resident voices a point of methodological limitation that will be discussed in later chapters.

As this chapter serves as the foundation for empirical findings to present back to the participating facilities, it is necessary to include even the experiences that overlap among facilities to be able to present a full depiction of each. The subsequent discussion chapter will focus on the tensions among and within facilities as the experiential building blocks of, and understood through, a relational landscape of LTC framework.
5.2.1 F1

F1 Family: Social Psychological

Flexibility

“If someone decides that they don’t want to get up until 11 here then they don’t have to get up until 11. They do things when the patients are ready so when my mom’s not in a good mood, she doesn’t need to take a bath and they can do it tomorrow. I see that they try to go with the flow that way.”

This experience directly echoes the stated goal of care in PCC to maintain and enhance personhood rather than to complete various care tasks. The example of allowing residents to follow their own sleeping schedule was commonly stated as an illustration of the care approach and it is generally understood by families in this facility that residents are given a choice in these matters in terms of what and when care tasks occur. ‘Go with the flow’ was a phrase that was used a number of times to describe the approach to getting care tasks done in a way that does not disrupt the residents daily routine and it succinctly describes the general attitude towards the objective of care within PCC.

“I think like housekeeping need to be treated like staff that get to know the people, not just doing their job, and I see that here. They talk to them, how are you today and all this.”

Here is described the other aspect of flexibility as portrayed by family members regarding how they notice the staff’s fluid roles within F1. All staff members are expected to ‘go with the flow’ and take time from their tasks to talk to the residents and get to know them. Although direct care staff have the most access to residents, it is often tertiary staff members such as housekeeping who have the most opportunity to get to know residents as their interactions are often less stressful or forced. Family members noticed this type of role flexibility and agreed it played a major role in they and their loved one’s experience of the facility.

Atmosphere

“I don’t know how they do it, but I think they’re almost unfailingly cheerful, respectful, warm, they always call him by name and they always come up close to him so I think he’s aware of them.”

Family members in F1 expressed a general warmth in the social-psychological environment through friendly interactions between their loved ones and staff. This is often
expressed as a contrast to institutional settings and again aligns with PCC’s personhood maintenance goal where the warmth in the atmosphere comes from acknowledging residents in a certain manner that amounts to a ‘home-like’ environment. Employing calm, cheerful and respectful language that respects the wishes of residents plays a major role for family members in creating a socially warm environment.

Relationships

“They do whatever they can to satisfy the needs of the residents and I feel like I’m part of the care team. When I come in and my mom is doing activities I’m comfortable and welcome to come in and participate with them so it feels very inclusive.”

Relationships are the foundation of personhood according to PCC (based on Buber’s 1937 thought that ‘all real living is meeting’) and from a family perspective it was important that they feel they are part of the care team. Family members in F1 (mainly those who visit often) find comfort in knowing that their voices will be heard and that they are able to participate alongside their loved ones in daily activities. Family members noted that fostering relationships with staff and spending as much time in the facility as possible is a way to allow for and enhance the other themes from their perspective. F1 fostered these relationships through open communication and maintaining a welcome environment for families along with residents.

“In my case once a relationship was established staff was more willing to come to me and ask what my mom would want. It’s not something that happened the first day she was here but relationships take time and they are reaching out to me now and making better decisions for mom as a result. Once the staff began trusting me and listening to my input they were able to develop a stronger relationship with my mother.”

Family members at F1 noted that their relationship with staff members were reflected in the staff’s relationship with their loved one and that this was a mediating factor for the quality of care received. Staff was said to generally have a willingness to form a relationship with family members, but this was only the case for those who visited regularly as it was noted that trusting relationships take time and effort to form between both parties. This further emphasizes the important role that family participation plays in LTC. Many of the social-psychological tensions
with Gentle Care or PCC could be mitigated with increased communication between staff and family members particularly in the cases where the residents are not able to communicate their wishes effectively.

**Tensions**

“I think this person-centred or whatever is a way for them to say oh well that saves us a lot of time as I know that they have many other patients on the floor to deal with.”

The above quotes encapsulate the main tension from the family perspective as it relates to the general approach to care. While there was an appreciation for the flexibility that comes with PCC, for many family members the approach was viewed as more of a justification for not completing basic care tasks and ultimately saving time. This is based on a recognition that their loved ones do not always, or have not historically, make/made the best decisions for their care without the necessary persuasion. Many of the family members have been the sole care partner to their loved ones and as such, have developed their own individual approach to care that is based on their knowledge of and relationships with their loved one. These individual approaches often do not align with PCC as they involve a certain amount of persuasion to complete tasks such as those related to hygiene that they feel are required for the residents to live comfortably. Allowing for too much choice or flexibility in these types of tasks (such as bathing, brushing one’s teeth, etc.) was viewed as a tension as this type of choice was not part of their loved one’s previous lifestyle. The assumption from staff that anything the resident wants is what is best for them is often at odds with family members’ knowledge of their previous lifestyle and can be viewed as an excuse to not complete basic, yet fundamental tasks.

**F1 Family- Physical**

**Flexibility**

“Some facilities we visited were very closed off but this kind of gives you the ability to wander around the whole place so we like that. My mom can go to the kitchen at any time and down to the sitting rooms and she likes to congregate around the nursing stations so she’s not always alone in her room.”
From a family perspective, the physical environment was flexible in terms of how it is used by loved ones. Simply put, families noted that F1 is set up in such a way to allow residents to move around freely and as a result have access to an array of opportunities to engage. Although this facility is arranged into distinct areas, other than the dementia specific area, residents are free to make use of the entire facility and they are generally not bound by the need to be somewhere so that care tasks can be completed. This flexibility aligns well with PCC in that, from a family’s perspective, there is a choice for residents to use the physical environment in whatever way makes them comfortable rather than being forced into an institutional structure.

**Atmosphere**

“In general it’s a quiet and peaceful place and that is important to people living with dementia and most people here seem to have some form of dementia. Unlike a hospital where there’s always beeping and loud speakers, here it’s quiet.”

The physical atmosphere in F1 was often noted by family members to express a calm and quiet feeling and this was typically stated in contrast to institutions such as hospitals. Part of the home-like atmosphere that F1 is striving for seems to be limiting those sounds that are typically associated with acute care institutions to instill a sense of peace amongst visitors and residents.

“When I walk in here it just feels homey, there’s just a bit of warmth to it where others felt like just institutions….It’s just the feeling you get when you walk in like an atmosphere.”

In this quote, we see a ‘feeling’ exuded in the atmosphere that to family members feels home like. An inability to say what exactly creates this feeling of warmth was a common occurrence but again, it was often expressed as a contrast to an institutional feeling. The previously mentioned warmth in social interactions coupled with a material warmth from the physical environment lend themselves to a feeling of home that was commonly stated by family members.

**Relationships**

“Sometimes we sit on the upper balcony, sometimes we sit on the balcony across, there’s areas to have picnics, we’ve had family dinners here and my mother and I walk along the beautiful trails together.”
The physical environment was commonly stated by family members to foster positive relationships between them and their loved ones by providing numerous spaces for meaningful interactions outside of the resident’s room. Aside from the internal amenities and congregating spaces that F1 boasts, it also provides a walking path and beautiful outdoor areas where family members enjoyed taking their loved ones when they visit. This convenient connection to nature and the immediately surrounding area (in which many of the residents lived) allows for family members to engage with their loved ones in a relatively unstructured space which promotes a feeling of independence.

Tensions

“It’s not a home kind of place because you’ve got few staff, few recreation, not enough interaction. It should be more open concept so people can see other people and not just be sitting in their room waiting. My mom is seeking contact so maybe lower the walls and have more common spaces where there’s maybe people putting puzzles together from opposite ends or a big tv room where you can see them all.”

This lack of meaningful interaction was a common experience for family members. Many suggested a more open-concept layout of the facility to facilitate more interaction throughout. This facility along with F2 are arranged into a number of smaller ‘homes’ to minimize the institutional feeling; however, many family members experienced a lack of interaction among residents due to few engaging common areas to congregate. Although residents are free to move around the entire facility, many are unable to do so without assistance, so they are left with few options for engaging activities or socialization. Family members expressed a desire for more passive activity areas (where residents are able to take part at any time but never required to do so) as well as areas for open viewing of the facility for ‘people watching’ outside of their established sections.

F1 Staff: Social-Psychological

Flexibility

“We kind of take a different approach to time demands that are usually set when you come into a facility by letting them sort of go on their own time tables and what they want and what fits their previous lifestyle. We adjust to whatever’s
happening and focus on that person and what they need in that moment rather than try and push our agenda.”

Staff at F1 are guided by the needs of residents, rather than a strict schedule of tasks to be completed. In an effort to align with a resident’s previous lifestyle, they all stated that a flexibility in terms of roles and tasks is required to allow for individual choice for the residents in their day-to-day lives. The most common example was letting residents sleep in, but the foundation is to work around individual residents’ needs rather than forcing a facility-wide schedule. This aspect of their experience is at the heart of PCC and Gentle Care where the goal is to maintain personhood, a large part of which is the allowance of choice in when and what care tasks are completed.

Atmosphere

“The way that they see the staff interacting with residents or with each other here and the feeling of calm like home. It’s not hectic or people being run off their feet. Its people being happy in their job and everyone in the home shows respect for one another and the sound of laughter is a regular occurrence, which helps to make the space feel home-like.”

The social atmosphere at F1 staff said was intended to foster a sense of home through interactions between staff and residents that are jovial and respectful. Staff were generally happy in their positions in the facility and they said this manifested itself in a calm environment where they are able to interact with residents in a positive manner again emanating a home-like atmosphere.

Relationships

“There’s a woman here who I know one time used to paint or draw so I know it’s a comforting thing for her so when she gets agitated or forgets where she is I bring out pencil crayons and paper at reception and I have her just sit down with me and give her a picture of something to draw and it’s so special. I have 2 pictures from her in my office now.”

Staff said flexibility in care tasks and roles was made meaningful through relationships with residents that bring about knowledge of their historical and present preferences. In the above example, a staff member used their knowledge of the resident to justify stopping what they were doing to spend meaningful time with that resident in an effort to reduce agitation. Flexibility
allowed the staff member to meet the resident where they were, while a relationship facilitated knowledge of what would make the resident feel better in that moment. This facility was said to promote these types of relationships between staff and residents and the staff noted relationships as forming a major part of their experience.

_Tensions_

“You got other girls like me, head to toe, even their backs you know what I mean? Put lotion on them and everything but some staff just don’t care they might not even wash the residents and so yeah, I think it’s just laziness. They’re in a rush to get nowhere, they’re not cleaning the residents so like their just more worried about getting more time on their hands afterward but when your resident smells you know, come on. I don’t believe gentle care comes in for them at all. This stuff is common sense and some people have it and some people don’t right?”

This quote underlies a common tension amongst staff at F1 where the facility-wide care approach is seen to be less important than individual staff member approaches or abilities. Often cited as a ‘knack’ for caring, the main thrust is that PCC already exists in staff who have that disposition and cannot be taught or engrained in those who do not have it, rendering it not as important to quality of care as more important to individual temperament. At worst, this amounted to some staff viewing others who do not have the ‘knack’ as using a flexible approach to care as an excuse to not complete basic tasks or to complete them in haste.

_F1 Staff: Physical_

_Flexibility_

“We think of Gentle Care and we think of what would work best like for instance a lot of people say our dementia secure area really needs to do a full circle because right now It’s like a C and these guys need to do circles, they don’t need to come to ends, so that’s something that is in our planning for changes but the management in here before did their best.”

Many staff members of F1 recognized the need to adjust the physical environment to meet the diverse and evolving needs of residents. The above example cited (which may also be seen as a physical tension) was in the dementia specific unit which is shaped as a ‘C’ rather than a continuing circle. Rather than forcing the residents to adapt to the environment, the staff acknowledged the need to, and plans to, rebuild that area to better fit the residents. This
represents a flexibility in their attitudes towards the physical layout which, for them, should be adjusted to suit the residents and not the other way around.

**Atmosphere**

“The look gives it a feeling of home as well. Just the paint colours and we have artwork throughout the home and a lot of it is made by residents who have been here or are still here.”

A homelike atmosphere at F1 came from the physical layout through features such as calming paint colours and resident-made artwork. To display pieces of art made by residents acts to foster a feeling of ownership over the space for residents as well as providing a meaningful activity. This ownership or autonomy is meant to harken back to the concept of home and was an often-cited example of how the physical environment is used by staff to promote a sense of home for residents.

“The colours inside are very inviting and brings a lot of light inside which is different than a hospital where everything is just dark. We have murals all over the place especially in the locked unit there’s flowers and paintings and I feel that that helps people that want to engage with the environment and be more tactile.”

Here, again the use of colors and access to light was a common theme for staff and this was typically juxtaposed with the feel of an acute care hospital. Additionally, features such as murals, flowers and paintings promoted an engagement with the physical environment by stimulating the imagination of residents, particularly in the dementia specific unit.

**Relationships**

“I think having smaller units so it’s not just one huge dining room, every unit has their own dining room which feels more intimate so you get to know your tablemates and it’s a quieter environment and easier to feel comfortable if you’re shy. You get to know our main staff and develop a closer relationship than you would if they were all grouped together.”

F1 is separated into a number of smaller units each with its own dining room and recreation area. This partitioning allowed for increased opportunities for social interaction and those interactions occurring in a quieter and calmer environment than possible in one large space. As a result, the smaller units were often credited with fostering not only quantity but also quality of relationships
between residents and staff as each unit evolves its own character based on the individuals occupying it.

*Tensions*

There were no physical tensions discussed by staff at F1. Many staff members did mention that the dementia-specific unit could be improved with a circular shape to facilitate wandering; however, they all viewed this as a rejuvenation that will take place when/if the ownership have the resources. It was a structural design error that occurred before the facility implemented their current care approach so does not reflect an outcome of the approach itself.

**F1 Residents: Social-Psychological**

*Flexibility*

“I get my Toronto paper that I just sit with my coffee in the morning and that’s my morning, I start, I do the same as I do at home eat my breakfast, and then I go back to bed. Oh yeah, I don’t, yeah, I like to sleep in so they let me do that.”

Residents at F1 enjoy the freedom of having the flexibility to go through their day at their own pace. Many cited the ability to sleep in as a benefit that is in opposition to a strict, regimented daily routine emblematic of a task-based care approach. This is a very simple but representative example of the benefits residents feel from an approach that focuses on their needs rather than the facility-based needs and basic allowances such as this were commonly cited as drastically affecting their quality of life.

*Atmosphere*

“I like the staff they are very, very good to me. Otherwise we’d probably be very unhappy, right. Yeah, they make the building, not the bricks. They make it feel comfortable. Yeah, not the bricks. I think they’re caring, genuine, caring. And they treat us well don’t they? They treat us like people and yeah, they’re pretty good, or I wouldn’t be smiling here today would I? No. They take care of everything for us. They’ve gone to pains to make sure we’re not lacking much. Just like a little world, that’s a good description, it’s a little world.”

The residents at F1 felt that their interactions with staff were the most important aspect of their experience. They viewed their personhood as affirmed through the interactions with staff which were said to be loving and compassionate. Residents did not have much to say about the physical environment which might be viewed as both a positive and negative aspect of the
experience. In a positive light, the lack of emphasis on the physical environment shows that it is not a detriment to their quality of life and may support them in passive ways that are taken for granted and therefore were not brought up even when prompted.

The description of the facility as ‘a little world’ was indicative of the feeling of safety and security where residents felt that they had little to worry about. This does not necessarily equate to the feeling of ‘home’ as advertised by the facility, but it certainly shows that the staff are attending to all of the basic physical needs of the residents who I interviewed.

**Relationships**

“They care about you here and what you’re doing. You’re not just a statistic here, you’re a person which I like very much.”

“I like them all, we share jokes whoever is working with you for the day. All the staff are friendly I’m really amazed.”

The general feeling from residents at F1 was that they felt as if staff treated them with humanity and compassion that affirmed their personhood and identity. This does not seem like a novel outcome due to the pervasiveness of PCC over the past 30 years as it is the foundation of the approach. Residents at F1, even those who were not happy to be there, expressed gratitude for the social behaviour of staff which in many cases was the only positive aspect of their experience in the facility. The relationships between staff and residents were often cited as meaningful ones which made up much of the positive outcomes for residents. It is important to note that this is not a given, nor is it a neutral outcome or part of the experience. Staff at F1, guided by the Gentle Care approach that is underpinned by PCC, make a conscious effort to treat residents like people, not disease states or statistics.

**Tensions**

“A lot of other people get looked over, they don’t get their health issues brought up. Because it’s only one doctor and there’s not enough time, yeah. The only time I’ve had to talk to the doctor was one day when I came out of one suite and she was coming out of the one across the hall and I approached her I say, are you the doctor, she said yes I am, I said I’d like to talk to you, and I talked to her in the hall for about 5 minutes, that was my longest conversation with that doctor. That’s not very much.”
Weighing against the quality of staff was the general lack of staff perceived by residents at F1. This amounts to how much time is spent waiting for care tasks and/or medical procedures to take place. This is a common theme amongst all groups and facilities and seems to represent a systemic or policy-based critique of funding allocated to LTC facilities. With that being said, it is possible that this perception from residents arises through a mismanagement of current staff resources stemming from the care approach. More likely, the perception is the combination of both systemic and facility-based tensions which amount to residents at F1 feeling like there are not enough staff where the reality of understaffing is coupled with an underdeveloped approach to make the most of current staffing levels. Regardless of the underlying explanation, this was an often-cited tension from the resident group at F1.

“My worst thing would be I don’t see my family enough. I don’t, that’s not enough. You can’t see them every day, no, they’re too far away. It’s too hard on them, they work. They’re good, they’re really good, my family’s good, we’re all good yeah. I think we all have caring families. I’d like to go home more.”

Resident experiences at F1 were heavily mediated by family participation in their lives. Residents were generally more interested in speaking about their family visits or lack thereof, than their facility-based experiences. Moreover, residents who had family members who visited often (some every day) and were available to take their loved ones out more often expressed the highest level of satisfaction with their lived experience.

**F1 Residents: Physical**

**Flexibility**

“This year I bought some tomato plants that I usually bought for my friend and she decided not to have a garden so I came back here and they gave me a little patch so you can choose your own little jobs, I also feed the fish, I could work all day they should start paying me.”

Gardens and outdoor spaces that allow for residents to bring their own plants and interact with in a way that they choose were often mentioned by residents as an aspect of the physical environment that allowed for creativity and choice. Those who were mobile enough to access these spaces appreciated the freedom and enjoyment they provided.
Atmosphere

“Generally the building its beautiful and they keep the whole building nicely decorated and we don’t have fancy pictures or anything but it’s all pictures done by residents and they’re very good. It’s surprising you don’t come here and there’s a great big fancy painting.”

The residents at F1 noted that a warm, home-like atmosphere was fostered through the décor in the facility, specifically citing the array of pictures displayed throughout the facility that had been created by residents themselves. This constant physical reminder of the celebration of resident accomplishments made the residents feel like they had some ownership of the space. They were very proud of these pictures, often walking me through the halls to pick out their own or those done by a resident that they knew.

Tensions

“I’m on my own, I go for supper and there’s nothing to do to really take my interest. I’m not given work to do.”

Some residents were critical of opportunities for engagement provided by physical environment while others were pleased with them. This points to the need for individually pointed activities to be focused with those having negative experiences or those that require more assistance. In general the physical environment was not as emphasized as much as the social-psychological aspect for the experience of residents at F1. This group focused on interactions with staff, family and other residents as the most important factors that make up their experience. While the physical environment at F1 is aesthetically pleasing, those residents who expressed negative experiences were more concerned about its ability to provide opportunities for engagement – its functionality, rather than its aesthetics. This tension highlights a theme that is explored further in Chapter Six regarding the broader theme of home and homelike located in both geographical gerontology and critical gerontology literature.
5.2.2 F2

F2 Family: Social-Psychological

Flexibility

“Even the maintenance man would stop in the hall and talk to my mother and understands how to interact with her which seems beyond his responsibility but it’s like everyone in the building is involved with patients care.”

This quote exemplifies a common aspect of the Flexibility theme from the family members’ perspective of F2. Flexibility in both tasks and roles for all of the staff (not only direct care staff) was a key part of the experience for family members. Witnessing these values from staff provided family members with a level of comfort knowing that their loved one was being acknowledged socially this way by all staff members.

Atmosphere

“I’d asked her about one of her sisters visiting and she said yes they’re coming to my place so she called it her place like this is her home. Nothing that she can articulate but she’s actually even said on a number of occasions about two different staff members ‘oh she’s a good mother’ so they’re interacting with her in such a way that she feels home and she knows it.”

Family members at F2 recognized a home-like atmosphere mainly through noticing how their loved ones described the social-psychological experience to them. In the above quote, the resident described F2 as her ‘place’ which came across as how someone describes their home. The resident referring to staff members as family members such as ‘mother’ shows family members at F2 that although residents may not know precisely who the staff are, they interact with them in a way that gives residents the feeling of a loving and comforting relationship similar to one you find in a family home.

Relationships

“Certain PSWs know that she loves to have her makeup on, she never walked out of the house without makeup so it’s great when I come in and the staff has her make up on and hair done up. She went through a bit of a delirium and hasn’t been great but I popped in the other day and she had her hair done and she was back to herself. Everyone knows our name when we come in here, they know who we’re there to see and will tell us if another family member’s been in.”
For family members at F2, relationships are the foundational aspect of the experience. This, similar to F1, is what allows for flexibility which in turn helps to create a home-like atmosphere by providing space and time to allow residents choice. The above quote shows how a family member recognizes the relationships between staff and residents through staff having knowledge of individual preferences (such as make up and clothes) and creating an opportunity for those preferences to be met even if the residents cannot express them explicitly. Moreover, family members appreciate that the staff at F2 take the time to know their name and which resident(s) they are there to see. Although seemingly mundane, this basic acknowledgement of family members goes a long way to make them feel involved and accepted in the facility.

**Tensions**

“The problem is that they basically try to allow the person to do what they want to do but the other thing is that they need to continue to get people involved. My sister is quite content to sit here and read books but I think she needs to get to know people and go out. Obviously it’s an adjustment but I think I would want to be out talking to people.”

Similar to F1, family members in F2 noticed that the amount of choice and flexibility offered to residents is not necessarily leading to a high quality of life. This quote exemplifies family members’ issues that allow residents to stay in their comfort zone and allow them to withdraw from all social interactions. Family members were concerned that a lack of persuasion to engage socially might lead to further isolation.

“They didn’t do kind of an initial assessment of his cognition and so they would be coming and offering him choices that he wasn’t capable of making and I’ve had to coax them saying there’s no point in asking him if he wants something to drink, you just have to get him something to drink. You need to make choices for him.”

Here is a quote from a family member who noted that it is often necessary to make choices for her loved one rather than always consulting the resident. She is concerned that staff at F2 needed to garner more information about her loved one’s ‘condition’ and past life to be in a position to make informed decisions about her current care requirements. Too much choice is seen as contributing to agitation for residents who have not necessarily always had to make a
choice about basic care needs. The balance between autonomy and vulnerability underlies much of the tension in the social experiences for family members at F2 where sometimes residents are not in a position to properly make certain choices and family members would prefer in these cases that staff knew enough about the resident to make an informed choice.

“The thing is that everybody’s different. It is my sister but I have my own life and family. You look and you say we need to get up here and the weekends come and go and we do not get up here as often as we need to. It must be sad for the people in here to not have anyone come in, it’s a lonely place even though it’s a nice place.”

This describes the main tension within family members struggling to visit their loved ones and is out of the facility’s control but is still worth mentioning due to its common experience. Much of the experience for residents was dependent upon family visits as much or more so than facility approaches. Similarly, family members were affected by feelings of guilt for not visiting enough and/or the general plight of their loved ones as they try to support themselves and at the same time stay involved. This is a structural tension, but facilities can support family involvement by fostering a welcoming environment and including them in activities.

**F2 Family: Physical**

*Flexibility*

“It was great when he first moved in to be by the door as he was a businessman so he knew everyone. Then with Parkinson’s it was distracting him so they picked up on that and would give him choices of spots. They used the environment in different ways to adapt to his changing condition.”

Flexibility in the physical environment was displayed for family members at F2 by their noticing that staff made use of the physical environment to support the historical and changing needs of residents. Family members noticed that many staff members were aware of the residents past lives and used that information along with their present capabilities and needs to make decisions about how they would best shape the physical environment to support them.

*Atmosphere*

“Some new facilities look like hotels whereas this looks more like a ski chalet. It’s kind of spread out, it’s only two floors. Other places feel more like a high rise or hotel and I just like the feeling of this building better.”
Similar to F1, F2 is partitioned into a number of areas that each house approximately 25 residents. It was often cited as having a ‘cottage’ or ‘chalet’ feel by family members which might be interpreted as a kind of home away from home. This is in contrast to the more rigid and institutional feel of a high-rise apartment or hospital. Generally, there was much less use of the term home from participants of all groups at F2.

**Relationships**

“My mom was a big gardener so when she first came in here they got her involved quite a bit on the patio around the garden beds and they’d get her busy picking weeds as she loved that I think its nice that they have different activities that might interest different people.”

In the above example the gardens were a perfect part of the physical environment for the family member’s loved one to enjoy as that was something that she had done in the past. Many family members acknowledged the number of activities that the physical environment at F2 provides for residents and the relationships that staff at F2 had with residents that allows them to guide the residents to appropriate opportunities for leisure.

**Tensions**

“It feels small for the number of people for a person like my mother-in-law who’s not as social as the others and gets forced into a dining room with lots of people but she doesn’t recognize those people. She’s lost weight since being here and I don’t know if it’s her giving up or the busy environment during meals.”

A calm physical environment was often cited as an important aspect for family members at F2 and one of the main tensions with this arose in the dining setting. This family member noticed that her loved one had lost weight since moving in to F2 and was concerned that it had to do with the busy dining setting which forced her to eat with 25 plus people who she did not recognize. This is a difficult reality for many LTC facilities as there is not enough staff or space to provide ideal dining situations catering to each individual resident’s preferences. Family members mentioned that dining in large groups in a tight space was the cause of much agitation for their loved ones who were used to dining at home with a few, trusted companions.

“To allow for more flexibility I would like to see more individual activation time. It’s hard, my sister came in one time and the description is they’re all in the
common room and there’s music playing and she said its like they’re chauffeured in.”

‘Chauffeured in’ was a term used by a number of family members who were concerned with the activities for large groups and how their loved ones were being rushed to these activities in which they may or not want to take part. This is largely due to a lack of resources for activation staff, making it necessary to efficiently move residents around to activities that do not cater to individual interests. Family members expressed the need for more individual activation time (activities) that caters to resident interests instead of the predominantly large group-based activity approach.

**F2 Staff: Social-Psychological**

*Flexibility*

“Everybody’s an individual so it doesn’t always meet the timelines or whatever of the staff so it’s pretty individualized and centred around the residents. We try to let them make decisions and go around their wishes and their time.”

Staff at F2 noted that the care they deliver is based on individual wishes rather than a strict task-based timeline. They take pride in giving the residents a choice about when care tasks are completed in an effort to maintain the dignity and diverse previous lifestyles of the residents.

This type of time flexibility for staff is common in facilities espousing forms of PCC as their fundamental objective is to maintain and enhance personhood. The most basic example of meeting this objective is allowing residents to keep to their preferred hours of sleep.

“You kind of have to go with the flow because a lot of the residents are not cognitively there so you’re trying to help them but you have to have a lot of patience and understanding. You have to be here and there and kind of juggle because it’s based on the resident’s needs. You have to work within a routine without a routine.”

This quote includes the commonly stated approach to ‘go with the flow when interacting with residents, where the ‘flow’ is guided by individual residents’ needs and wishes. Many staff members at F2 repeated this phrase as the guiding principle for interacting with residents in a flexible manner and that to do so, staff need to have a level of patience, compassion and understanding. Whether or not these traits can be learned or developed through an adherence to
the facility-based approach is a point of discussion for the next chapter but it was clear that the individual traits necessary components of the culture they espouse in this facility.

“At a certain age the important thing is quality of life as much as that might go against clinical assessments of what good care is. Here that’s important and if all their eating is cookies and pudding and they’re 98 years old that’s great.”

Above is an example of how staff at F2 have adopted a flexible and individual choice-based approach where they recognized that quality of life can span beyond clinical assessments and into the social realm. In this scenario it became even more important to adjust for the individual resident’s wishes over clinical assessments and recommendations.

Atmosphere

“We use a lot more first names than we used to, it’s a lot more casual and warm like not so formal.”

A subtle but effective way that staff maintains a warm, home-like atmosphere in F2 is to use first names when referring to residents. This was stated as a change from the past where there was not as much emphasis placed on using or even knowing first names. Additionally, underlying the outcome of using first names is an expectation to get to know the residents that is the main culture shift to which staff are referring. Displaying casual and warm relationships through acknowledging residents and family members on a first name basis is a simple but integral piece of their experience that is informed by the care approach.

“Rather than automatically go to supplements when somebody has a nutritional problem we ask how we can put actual food into them. A food first approach is better than pills in terms of quality of life and it’s just less clinical to go that way.”

A warm atmosphere was created in a subtle way through a ‘food first’ nutritional approach at F2 that favours real food over pills where nutrition is to be considered. This approach along with similar anti-restraint and psychotic medication policies provide less of a clinical atmosphere and generally enhance the quality of life for residents as a result. We can see again how LTC facilities generally view home as a construct that is simply the opposite of an institutional approach where they seek to instill a feeling/atmosphere of home by limiting the
clinical aspects. While not problematic in this experience, this limited conception of home, which is a shared goal of all three facilities, is a jumping off point for an expansion through engagement with home as a concept in geographical gerontology in the next chapter.

Relationships

“We always work as a group and that’s what makes good staff. That’s just how we work in here, you have to, you have to be able to work as a team and trust your coworkers or else its terrifying.”

As with F1, relationships are fundamental to PCC as they allow for and inform the requisite flexibility in F2. Staff members at F2 were said to work well as a team and shared close relationships amongst themselves as well as with the residents. This was said to be an important aspect of their experience as not only is it a difficult job, but the task and time flexibility makes it difficult to rely on anyone to complete necessary care tasks in a certain time so staff at F2 need to develop a trusting relationship and communicate what needs to be done effectively.

“A lot of people are afraid of coming here but a lot of it is common sense you learn how to, just by experience with them, form a relationship with them and when they pass it’s like losing a family member. It’s hard.”

Staff members noted that the close relationships they form with residents which are required to provide the quality of life they strive for lead to strong emotional reactions when residents pass away. The method of forming these relationships was using a ‘common sense’ approach rather than strictly adhering to any care approach. This is another example of a strong emphasis from staff at F2 on individual traits or having ‘the knack’ for caring as more important than the facility-based care approach particularly in the social-psychological realm where interpersonal traits and skills are central.

Tensions

“There’s just not enough staff and there’s more and more expectations put on you every day and you’re not getting more of anything. I don’t feel like I have enough time to do things, like I don’t feel like we are able to give residents the time that they deserve you know where we’re running around and I have 50 things to do and somebody is crying and I’m trying to prioritize and I’m not able to just sit with someone.”
The above quote contains much of the main thrust of the tensions felt by staff of F2 in the social-psychological realm. As with many other facilities, F2 maintains a staffing level that allows for them to spend meaningful time with residents who the staff said mainly were in search of company and that this can be mediated by family visits. Adding to this lack of time available for simply being with residents is an increasing expectation from management, family and themselves to provide a quality of life that in the end staff feel needs to include that level of company. Many staff members at F2 felt immense guilt and frustration as a result because the supports did not align with the ever-heightened expectations.

“For some people it’s just a job but a lot of us don’t view it that way…you’re either that way or not regardless of the institutional practice. People who are really structured in their own life struggle a little bit and can be very task-oriented.”

This staff member expressed the common perception amongst staff at F2 that individual traits are more important than the facility-based care approach. She felt that the traits required to provide good care such as compassion, flexibility and patience cannot be taught or learned through following a particular care approach. Many of the staff believe someone who is not already gifted in these fundamental personality traits cannot acquire them through any training. A ‘Knack’ for caring as well as an engrained interest in caring for older people in particular was the main prerequisite for providing good care and this feature needed to have already been developed before being exposed to any care approach.

F2 Staff: Physical

Flexibility

“They took the murals off because people thought they saw flowers and trees and saw it is a place to go the washroom so now at the end of the halls they’re doing little sun areas with activities down there and chairs and put murals on the windows.”

Staff at F2 did their best to adjust the physical environment to the changing needs of the residents. The above example is from the dementia-specific unit where it is common to have murals on the exit doors to minimize agitation for residents who wander. Noticing the adverse
effects from the ‘flowers and trees’ murals they found alternative ways to use the space as opposed to forcing residents to adapt.

Atmosphere

“We have the six areas so we have smaller communal dining areas which certainly makes it less chaotic and quieter. We bake things in the areas so you actually get the scent of muffins which I think gives it a homelike feel.”

In a large facility such as F2 staff recognized the benefits of breaking off into smaller units, each with their own dining area. This led to a calmer and less chaotic environment which reduces agitation for residents and allows for more home-like daily activities such as baking muffins. The smaller contained units were intended to provide a more home-like environment mainly because they simply felt quieter, calmer and less busy than one large space. This was, however, also a main point of tension in the physical environment for staff as discussed below.

Relationships

“I think the smaller units are nice because they keep the staff consistent so that they know each other they’re comfortable with each other.”

The above quote shows the general perspective that staff at F2 had about how the smaller units support a consistent staff presence for residents and other staff members. Teamwork and relationships among staff members were an important aspect of the experience at F2 which was supported in the physical environment by consistently working with the same staff members in each unit to build trust and comradery.

Tensions

“I know a lot of older nursing homes that look a lot more run down that are more homey than here. Here is more nice but it’s more institutional...It's like I have coworkers that I haven’t even met. If the goal is hominess than we’ve achieved that more through the staffing than in the building.”

“It’s just not as homey as the old building. I don’t think the building was built very practical but they have their fancy gardens and balconies and that but there’s just not time to get them out there unless you’re activities.”

The above quotes are grouped together to represent the underlying tension in the physical environment from staff’s perspective at F2. Although it was purposely built to emulate a home, the experience at F2 does not necessarily align with that stated purpose. The main thrust here was
that although it is objectively nice to look at, in practice the building does not achieve a home-like feel for the staff. Alternatively put, ‘home-like’ does not equate to home. This was mainly due to the large size which, in spite of the smaller contained units, led to a lack of staff interaction and resident activities. Staff at F2 experienced frustration when the physical environment looks ‘fancy’ but is not as functional or supportive for them in terms of its effect on building relationships among staff or meaningful engagement with residents. They viewed the home-like aspect as an achievement in the social-psychological environment arising in spite of, rather than as a result of the physical environment. The main theme to recognize here that will be discussed in the next chapter is that ‘home’ as a concept is not made of bricks and mortar and its physical aspects are more elusive and nuanced than can be contained in a blueprint or building plan. Another main theme that this relates to is a high staff turnover, where the effort to consistently group staff together in the smaller units does work well due to systemic staffing issues. The physical environment cannot make up for structural issues with workers.

“I used to work on the old Alzheimer unit and it was built in a circle like they could walk around but they can’t here so it’s not as practical. The floor itself should have been a circle, they get down to the end of the hall and they get stuck. They wander a lot looking for a way to get home and the hallways just stop.”

Above is a more specific echoing of the underlying tension in the physical environment that, well the facility is generally aesthetically pleasing, there are aspects that are just not practical for the realities of the staff and residents. The shape of the dementia-specific unit was a common tension amongst staff who felt that it was a great oversight to build the floor with two clear stopping points, rather that the circle shape in the old building. Notably, both F1 and F2 (the two facilities that have dementia specific units) share this tension and I did not hear any positive responses about the current shape in either facility.
F2 Residents: Social- Psychological

Atmosphere

“Well it isn’t home, but if I have to be in a place like this I think this is the best place around, I really do. It’s friendly and the staff, even if it’s not your immediate staff, they all know your name.”

Residents at F2 were complimentary of the quality of staff. They all appreciated the friendly demeanour of the staff and generally recognized the benefit of being called by their name as a recognition of their personhood. This shows that staff at F2 are supporting the personhood of their residents in alignment with PCC and was an often-repeated experience from the residents who had much more to say about staff interactions than they did about the physical environment. Similar to F1, the emphasis on the social environment from residents may be a result of a supportive physical environment or a lack of engagement with the physical environment due to a lack of opportunities to do so. When asked what they liked about the facility, F2 residents mainly echoed this sentiment about friendly staff. The above quote is one of the more lucid versions where there was a clear separation of ‘home’ and the facility but a recognition that it is the best option mainly due to friendly and supportive staff members that led to a supportive social environment.

Tensions

“You can see the difference in the younger people doing the service, and so we sort of got to wait and see how many of these come in and are as interested in the job as the older ones. You can see quite the difference in the personalities of the younger staff. They don’t give you that opinion that they’re tremendously interested. It almost looks like they don’t want to be in the role.”

Echoing the tension from the staff at F2, residents also noted a distinct difference between how they were treated by newer/younger staff members. They noted that younger staff seemed less interested or suited to working with older people and were generally undertrained for the role. Caregiving for older people is a difficult job, and one that requires not only the physical skills to complete care tasks, but also the disposition to complete them in a compassionate and caring way. It is unclear why younger staff members are not perceived to have these traits by residents, but this is a tension that can be addressed either through enhanced practical training or
stricter facility-based job requirements that may severely limit the already dwindling staff resources. Additionally, while the disparity of experiences drawn from different staff demographics certainly points to the need for an expanded and more nuanced approach to account for a more diverse staff, it also begs the question of how much of the experience of long-term care is guided by the approach. It is not clear whether essential traits such as compassion and empathy can be taught or policed in any context according to the staff participants.

**F2 Residents: Physical**

**Atmosphere**

“I chose here because suitability to live in, space, and uh most of the other homes there, everything is very small or like your house would be, whereas you come here and the living room is huge, because it’s a hall down there and stuff like that. So you have a lot more even though there are 168 of us in here plus the staff, it doesn’t seem that crowded.”

Residents at F2 appreciated the aesthetic and the space that the facility has to offer. The physical aspect of the environment provides a relatively open-concept space that amounts to a freedom of movement and a feeling that it is not crowded. Interestingly, rather than equating the feel to their past home, the residents at F2 often mentioned that it has its own ‘cottage-like’ feel that some appreciated while others less so.

**Tensions**

“I read a lot because there’s not much else to do, that’s all I do. I don’t get out to the garden, I can’t go on my own and everybody’s too busy to take you. Sometimes my son comes and he can take me. They have bridge but I don’t play bridge but I like cards, when my son comes to visit we play gin. I’d be lost without my sons, they’re so good, they visit.”

Above is another example of the results of the staff shortage in F2 as well as family as mediating factors in the experience of LTC. The theme of ‘waiting’ is echoed in this resident’s experience where she would like to visit the gardens but cannot get there without help from staff who are often too busy to do so. As a result, this resident’s quality of life is highly dependent on her sons visiting, an experience that was very common amongst residents at F2. This aspect of their experience can help explain the lack of discussion from them about the physical environment as much of their engagement with it is only made possible through family visitation.
and participation. Residents who do not have visiting family members are disproportionately affected by this perceived lack of social engagement amongst residents and staff.

5.2.3 F3

F3 Family: Social-Psychological

Flexibility

“One thing that I noticed around here is that everybody jumps in if they see something. Especially, if they see somebody having a hard time.”

Family members at F3 were pleased with the staff’s ability to support each other and the residents in any role or task that was necessary at any time. In this smaller and more hectic environment, the staff is in closer quarters than the other facilities and are able to quickly notice tasks that need to be done. Family members noted that all staff including those that are not direct care were able to step in and spend meaningful time with their loved ones. In a smaller and more hectic facility such as F3, this versatility plays an integral role for the residents’ quality of life outcomes and family experience as a result.

Atmosphere

“A lot of them have been here a lot of years and it really feels like family here, everybody has a close interpersonal family-type relationship. It’s like a giant family home here and everybody’s a part of that family.”

Notably, family members tended to refer to the atmosphere as that of a family, rather than ‘home like’ as in the other two facilities. This semantic shift is reflected in the social-psychological atmosphere through close-knit staff relationships formed throughout many years working together. The experience of a family-like environment is representative of a strong focus on social supports noticed by family members at F3.

“Being in this environment you become a product of it and here it is so open and friendly you become that. Even the new guys do because you can’t teach empathy and compassion but you can absorb it and I think that plays a role here.”

Continuing with the family-like theme, this quote reflects the capacity of a friendly and open social environment to rub off on people who enter in which in turn further enforces the familial aspect. Family members at F3 recognized how the social environment there actually
made them more friendly and congenial as well as feeling secure about where their loved ones are.

**Relationships**

“I was very surprised and happy to see how personal relationships and they know people by name and even the ones that can’t speak you see their facially respond because it’s like their own loved one or spouse its just the relationships and that goes for all staff. It was just incredible how quickly the staff got to know my dad.”

Family members at F3 particularly noted how personal, sincere and important the relationships between staff and their loved ones were, and how large of a role this plays in their experience of the facility. Getting to know residents is the foundation for providing the type of care that they need as individuals and at F3, the family felt that this was a positive aspect of the experience.

“The staff makes the difference here, they put their heart and emotion into it because they have relationships with these people and everybody takes it personal. It’s not just about getting a job done here.”

The idea of ‘taking it personal’ was a common theme among family members at F3 who noted that not only do staff there form working relationships with residents, but they deeply care for them on a personal level. This is another way that F3 promotes a family-like atmosphere. For F3 family members, the staff provided more than care tasks for their loved ones and formed deep and sincere relationships with them.

“I was sick for a month and I had a nice note from the staff hoping I was feeling better. They recognized that I hadn’t been here for 2-3 weeks and included an obituary note from the daughter of his old roommate. So it doesn’t just extend to the patients but also the caregivers that come regularly.”

This is a specific example of how family members experienced their relationship with staff at F3. They noted a strong relationship between them and the staff (limited to those who come regularly) who take time to make their experience a meaningful one as well as their loved ones. The family members at F3 all spoke about experiences of having deep relationships with staff which often led to thoughtful specific experiences such as the one outlined in the above
quote. This was a very important aspect of the family experience at F3 who found it rewarding and comforting to know that the staff cared for them as well as their loved ones.

**F3 Family: Physical**

*Flexibility*

“They do the best with what they have.”

This comment was uttered a number of times by family members at F3 who recognized that staff at F3 did not have a very supportive physical environment to work with but was doing their best to make up for that by being creative and efficient with the space. There is not much room for flexibility in the physical environment at F3 as it was not built as a care facility so there were few examples of flexibility from family members.

*Atmosphere*

“Take a look at the board downstairs and see how long some of the staff have been here… there’s still two or three staff that have been here since my dad was here in 1981. You don’t work in a place like this if you’re not a loving person.”

A family-like atmosphere was said to be fostered in the physical environment at F3 through displayed reminders of its history with individuals as well as the surrounding community. Family members felt comfort in knowing the deep roots of F3 and being able to engage with these reminders throughout the facility such as the board displaying staff members’ history, some of whom have been working in F3 for over 20 years.

*Relationships*

“When you get into larger facilities there’s more staff there’s more turnover of staff and residents and there’s less chance of seeing the same residents. All of these people see the same residents every single shift and see each other as well so they find comfort in knowing and trusting each other because everyone is so giving and friendly.”

“In a large place where the halls are bigger there’s not that chance of interaction so they take advantage of that lack of space to make personal contact. It’s that personal touch that is here and is lacking on other facilities I visited.”

Family members at F3 felt that the smaller size and open concept of the facility (while it has its pitfalls) lends itself to building strong relationships by increasing the amount of time spent together and the chances of seeing a familiar face every day. Familiarity was seen as breeding
comfort and trust which are integral components of a strong relationship. A large quantity of interactions at F3, through its smaller size, is coupled with a high quality of interaction where the staff took the opportunity to provide a ‘personal touch’ that can only exist through a meaningful relationship.

Tensions

“My only complaint is the physical facility. The space is a bit small, but they can’t control that and how they work around that as a team is incredible.”

There were no tensions from family members at F3 in the physical environment aside from obvious aesthetic critiques of the layout. They viewed it as a limiting aspect of the quality of care but not an insurmountable one as it was made up for by the positive social-psychological environment. They realized that the building was not planned with a philosophy of care in mind and is not reflective of any care philosophy so they chose to instead focus on how the staff work around the shortcomings of the physical environment as a team.

F3 Staff: Social-Psychological

Flexibility

“Getting that feedback from the residents continually is important because quality is what they say it is and what we think is important might not be what they think is important so we make sure we revisit that as clients change and new ones come in. You gotta give them choices and you gotta be kind when you do this because you don’t want them to sit in a chair like a tulip. You have to be flexible to make time for them you really do.”

Staff at F3 expressed the importance of revisiting their values as residents change and present new and diverse experiences for them to support. In terms of specific care tasks, the staff at F3 all recognized the importance of allowing the residents choice similar to the staff at the other participating facilities but the differentiation here was the broader flexibility in values. In general, there was far less reference to a care philosophy amongst the staff at F3 than the other facilities. Interestingly, many staff members actively were against any kind of overarching philosophy and preferred an individualized common sense approach although those who did seemed to espouse an individual approach that aligns with the tenets of PCC but they were wary of the ability of a facility-based approach to affect individual values.
Atmosphere

“We try to include things from the community as part of the happenings here which I don’t think would happen in a big city so here we try to engrain it in the community as much as possible. This is an important place for locals who know the history.”

Staff at F3 noted that the facility made an effort to foster strong ties with the community by engaging with local events and participating in them as much as possible. They emphasized the historical significance of the facility in the community and used that to harness a feeling of community. This outward focus is at the heart of the atmosphere they are trying to create in F3 where the historical and present community ties are said to ‘make up’ for a building that was not made purposefully for LTC.

Relationships

“We have a lot of long-term staff so we tend to be…it’s more like a family even amongst staff. One thing about our facility, for the lack of décor, we make up for it with the staff…we’re friendly and bubbly and dancing and singing and kissing and hugging and we’re ridiculous actually…that’s the way it should be. We’re all friends and I think that’s where it comes from, not a philosophy but from us being close to each other.”

Staff at F3 relied on their close, familial and congenial relationships to provide the type of atmosphere for which they are striving. Recognizing the physical shortcomings of the building, there was a close bond amongst staff members which was the main thrust of their experience and overall approach. Notably, many staff members at F3 felt that their broad approach to caring for the residents arose more from their deep relationships with other staff members than any care philosophy.

“We just have a real connection with management here and that’s huge, they listen. If you want to talk to our administrator or Director of Nursing you just have to knock on their door and you can talk. They have an open-door policy here, they are really good that way.”

Staff at F3 also expressed a meaningful and deep connection with management. An ‘open-door policy’ for any staff members showed the staff that management are supportive and that there was a level of trust between staff and management that was integral to the culture of care they wanted to provide. This was certainly facilitated in a smaller facility, but the more
important aspect is the relationship itself that promotes open communication and trust between groups.

“There’s a lot of talk about their history and we’re the only ones they really get to talk to so not only are we here for them as a worker, we’re here for them as friends and family and they trust us, they tell us things. I’m so lucky I get to get into my car every day and visit my 32 grandfathers and 37 grandmothers. Working here has changed who I am for the better, I put my heart and soul into work and it makes me feel like I’m a better person when I get home.”

Lastly, the staff at F3 expressed strong relationships with residents that often were characterized by familial descriptions. The staff here were very emotionally connected with the residents and they recognized this as the foundational part of the experience at F3. The language they used to describe these relationships tended to be heartfelt and very expressive rather than synthetic as a recital of a pre-determined care approach. They cared deeply about the residents and showed that they carry these relationships with them even when they leave the facility.

Tensions

“I’d say in the next 2 years a number of us are retiring so we’re a bit worried some of the younger staff are not what I’d call cut out for the job. They just don’t have the interest in long term care. I find the young people coming in nowadays they just don’t have the patience. I really think that you can’t just go to school and then go in a facility and start to work.”

Social-psychological tensions amongst staff were fairly common in F3. Since many staff members had been working here for an extended period, they were wary of young staff members whom they viewed as less competent. There was an impending fear from the longer tenured staff members that once they retire there will be no one to carry on the level of care or strong ties in the community. For these older staff members, the newer staff did not have the experience or even an interest in working with older adults which is a perspective that caused the main tension among staff members.

“I feel like there’s not enough going on, there’s not enough activities for these people…get them out, get them to do stuff. Our activation staff is wonderful when they’re here but they need more stuff throughout the week, they’re bored, plain bored!”

Staff members also noted the lack of opportunities for resident activities, mainly throughout the week which amounted to boredom. This was not due to a lack of staff quality, but
more so a lack of time and resources allocated towards activities. I did attend a number of activities during the observation phase and they were all very well attended and appreciated, however, according to the staff there are simply not enough options.

“The approach is certainly not something they talk about a lot. You’re given the value statement to read but that as far as it goes and that’s pretty generic, ‘homelike’ and such. I go by my own philosophy and I wish some of the other people did the same”

The tension expressed here is one of individual versus facility-wide philosophical leanings where staff members felt as though they were more guided by their own beliefs than those espoused by the facility. In this case, PCC is no more than a collection of buzzwords and platitudes that do not truly move the staff.

**F3 Staff: Physical**

*Flexibility*

“I think that because of our limited environment sometimes we get more creative with the way we do things and we can do things a bit differently than a bigger care home. I think it breeds creativity and presents challenges that always bring attention to our core values”

Staff at F3 viewed the limited physical environment as an opportunity for creativity rather than an excuse to stop providing a high quality of care. In fact, many of them noted that constantly having to use the physical environment in different and creative ways led them to highlight and actively reflect on their core values on a regular basis. This kind of forced reflexivity about the physical environment and how it reflects core values keeps the staff engaged with their and the residents’ relationship with the physical environment in a way that is difficult to determine in a facility where the physical environment is purpose-built for LTC and as such was not questioned as much at the other two facilities. Rather than relying on the physical environment to produce positive outcomes on its own, staff at F3 stayed actively engaged with how it is being used.

*Atmosphere*

“Everybody’s in one big happy family in here, we don’t have a locked unit for dementia which I kinda like. Should they all be put in one cage just because they have dementia? I don’t think so.”
The ‘family-like’ atmosphere was fostered in the physical environment with the lack of ‘units’ or wards that section off residents and are common in larger facilities. Specifically, the staff mentioned that a lack of a dementia-specific area in the facility was representative of the family feeling and was made possible by keeping the facility smaller and emphasizing relationships so that staff could make informed care decisions about diverse individuals without categorizing them and ‘caging’ them based on disease-states.

“This was not a nursing home to begin with so it’s a little more homey and has its own personality. It won’t impress people that come down from the city but for people in the community its part of their community and this is where they want to stay.”

Interestingly, the staff at F3 appreciated the fact that the building was not purpose-built for LTC and they felt that this actually contributes to a more ‘homey’ feel and distinct personality. Here again, we see the emphasis on community and historical ties that show how staff view the facility as a part of the surrounding community rather than an insular, isolated construct. The feeling of family that is invoked in the facility is drawn from the significance it has within the surrounding community. F3 is supported and depended upon by the community to provide care for local residents and preserve a part of the area’s heritage. The building was not altered when it became a care facility, but its use was changed to align with the evolving needs of the community. On a smaller scale, this is how the staff views the physical environment of F3 and how its uses have changed based on the fluid and diverse resident needs.

**Relationships**

“I’ve worked at much larger facilities and found it more challenging. Larger facilities have staff thrown all over the place with people they’re not familiar with and just not being able to make those connections. When you see people more often you develop more relationships and trust and all those good things.”

This is a simple but important point that many staff at F3 made regarding how the physical environment effects relationships with the facility. It was noted that smaller facilities such as F3 nurture relationships by providing more opportunities to interact than larger facilities. Meaningful connections and trust are built through a high chance of interacting with the same
people on a regular basis. Staff at F3 valued relationships as their foundation of good care and they cited the relatively small size of the facility as one of the main features that supports strong relationships with residents and amongst each other.

Tensions

“Here there’s not a place for people who wander to do so safely. It can get very noisy and at the end of a 12 hour shift it’s a lot to take and people with dementia don’t understand the concept of giving people space anyways so they’re like you’re in my way move.”

The physical environment at F3 was not built to support long-term care and while this helps to provide character and preserve historic ties, it also led to some difficulties specifically with people living with dementia. Staff specifically noted the lack of space for safe wandering, a behavior that is typical of people living with dementia, as well as an overall lack of space leading to an often noisy and chaotic environment. This represents the other side of a smaller and less routinized facility where although there are ample opportunities to form relationships, there is a corresponding lack of personal space that caused some agitation in both staff and residents.

“The rooms are too small. You’ve got four beds into a ward and all you’ve got is a bed, a wheelchair and a little tiny dresser because there’s no room to have chairs to sit in a room. Even a semi-private is not big enough to me, they’re crammed in there like sardines!”

Above is another example of the shortcomings of a smaller and non-purpose-built facility. Staff at F3 noted that the resident rooms are often not a sufficient size for the quality of life for the residents that they strive for. This is the only facility where the staff felt that the rooms were insufficient however, again, this was balanced against the family-like social atmosphere they felt was making up for the physical shortcomings. Staff at F3 were looking for a balance between physical modifications while maintaining the family feeling and historical relevance of the current building which is not a simple task with limited resources.

5.2.4 Next Steps

This chapter has traced the diverse lived experiences of three versions of PCC. It has done so through the conceptual lens of Kitwood’s (1997) dialectic expressed as three emergent
themes that arose through an analysis of the interviews. These experiences were also coloured by my own perspectives developed through the observation phase in each facility. Tensions have been highlighted and will be analysed further in the next chapter as possible departure or expansion points (experiential gaps) into which we might gain a new understanding through an elucidation of a relational and spatially sensitive lens from geographical gerontology. As discussed in the previous chapter, the facility-based experiences will be further obscured for further analysis as the more general experiences shared within groups are highlighted. As all three facilities promote a PCC approach, it is that approach in general that this inquiry goes on to consider in an effort to contribute to a relational expansion of the general approach.
Chapter 6 Informing a landscape of long-term care through experiential tensions

“Just as Kitwood cautions the reader against accepting ‘neuropathic ideology’, so too should the reader be cautious about uncritically substituting ‘Kitwood ideology’. We must remain open to further scientific findings while we engage in critical examination of all new ideas from whatever source, and rigorously test them against experience derived from practice.” (Gibson, 1997, p.29)

In this quote lies the conceptual thrust of this project: a critical examination of PCC from its lived experience so that we can better match its theory in policy application. The application of an unfinished or underdeveloped theory can amount to unmet promises in practice or misplaced projections in policy. If PCC has become a stagnant figurehead of a theory, it is critical to engage with its experience further to re-animate it to better suit the populations(s) it aims to support and highlight those it, perhaps, ought to better support. This chapter expresses a further refinement of the empirical results, structured within the three emergent themes expressed in the previous chapter - atmosphere, flexibility and relationships that characterized participants’ experiences in environments informed by PCC. The results show an environment experienced as a home-like atmosphere employing a flexible care approach with the goal of forming meaningful relationships. However, within each theme there exists tensions in the experience where the PCC-based philosophy of care can amount to detrimental experiential outcomes that reflect broader conceptual tensions that make up the care experience.

The goal of this chapter is to tease out these tensions and present them as relational outcomes of the place-based experience of PCC. Portraying the experience in such a critical light serves to expose the practical shortcomings of PCC-based approaches in an effort to make conceptual room to continue Kitwood’s project of expanding the approach so it may better suit the needs of everyone involved. Additionally, applying such an empirical context (LTC experiences) to a conceptual framework that highlights the relational aspects of place experience contributes to the development of a landscape of LTC which has been noted as lacking in the discipline of geographical gerontology thus far. In sum, this analysis provides a contribution to
the advancement of a relational understanding of the complex transactions between older adults and place in the context of LTC. The broad connections to core concepts in earlier chapters is presented at the end of this chapter after having discussed the specific relational tensions in the lived experience.

6.1 Organization of the discussion

This chapter is structured around the three emergent themes from the interviews that were developed in the previous chapter to represent the experiential aspects of LTC environments informed by PCC: atmosphere, flexibility and relationships. The experiential tensions that were expressed within each theme are further organized in terms of the relational landscape of LTC framework expressed in Chapter Three. The framework considers an experience of place in terms three relational forces: collectivity, contingency and cultural differences. Filtering tensions for each theme through such a framework focuses and guides the discussion by providing a nucleus for understanding the tensions in terms of their relational aspects.

Notably, as discussed in Chapter Three, there were no tensions found that can be understood as being based on cultural differences and, as such, that part of the theoretical lens has been removed for this discussion. This is viewed as a methodological limitation and will be discussed as such in the final chapter. Further, the differences between and within relational aspects of an experience are entirely theoretical, as in reality all of these forces act simultaneously to make up a lived experience. Similar to the social/physical divide of the last chapter, this theoretical separation serves as an explanatory tool to link the tensions to those discussed previously in the literature in an attempt to bridge the salient disciplines and, perhaps more importantly, to sharpen the gaze on particular aspects of the experience for a more nuanced depiction – taking it apart to see how it works. While there are a variety of new quotes presented, a number of quotes representing tensions felt have been repeated from the last chapter. This chapter represents a relational approach to framing the experiences beyond that from the previous
chapter’s dialectic framework. In that sense, the same ideas are further filtered and refined in a way that is worth repeating the initial idea.

A final clarification is that not all aspects/sensitivities in the conceptual framework are represented in every theme’s tensions and there is considerable crossover between themes. In qualitative research such as this with humanistic orientations we might consider such messiness as designating a level of authenticity or trustworthiness as it is reflective of a nuanced and sometimes messy human experience of the world that is not meant to neatly fit any one conceptual lens. Further, this messiness does not preclude the production of knowledge as the particular lens may not address all aspects of the phenomenon in question, but it acts to highlight and unveil meaningful aspects for the particular inquiry. With this in mind, the specific limitations of this conceptual application are discussed in the final chapter following the discussion of what it has unveiled below.

6.2 Theme 1: Home

PCC-based approaches promote a home-like environment or ‘feel’ in contrast to an institutional or hospital-like one. They do so through considerations in the social and physical aspects of the environment, as shown in the previous chapter. The tensions in this theme largely arise from an undertheorized conception of home as a stagnant and homogeneously experienced phenomenon rather than as a dynamic relational one. Such an under-theorised version of home is borne out in the tensions that can be expressed as collective and contingent aspects of the experience of PCC-based LTC environments for each participant group.

6.2.1 Collectivity as tension(s) in home

“My mother gets wheeled into the auditorium and she can’t get out of there. She can’t hear, she can’t see and it’s just inappropriate. It’s not about Mr. Bojango up at the front, it’s about holding hands with each other so stop doing Bingo and rushing around trying to get people to participate in things when all they want is company because they’re isolated.” (Family).

“It’s not a home kind of place because you’ve got not enough real interaction. My mom is seeking contact.” (Family).
“I’d like to go home more. My worst thing would be I don’t see my family enough. I don’t, that’s not enough. You can’t see them every day, no, they’re, it’s too far away. It’s too hard on them” (Resident)

The above three quotes from family members and residents allude to an atmosphere that is reminiscent of an institution rather than ‘home-like.’ Due to its crowded nature and contrasting ideas between staff and family members about how much contact is ideal as well as the nature/quality of the contact the collective nature of LTC environments informed by PCC places limits on the extent that the environment can remind its inhabitants that they are at home. The above quotes describe a crowded environment but also one where the interactions are either vapid or even distressing for their loved ones, aesthetically pleasing environments where interactions take place but they cannot overcome or live up to recollections of home. While recreational activities and casual contact are generally thought of as part of a high quality of care, such activities need to be appropriate for individual residents attending them in terms of their capabilities and interests, and such contact is disorienting for some residents and should properly be focused on more thoughtful interaction rather than sheer quantity.

To sum this conflict up, while staff were often concerned with getting residents to activities (or busy meals) that they may or may not be able to enjoy, family members felt that their time would be better spent simply slowing down and engaging individually and thoughtfully with their loved ones. This conflict of expectations does not necessarily represent individual staff members as they would likely agree with the need to spend more thoughtful time with residents (see the below quote); however, it exists in the experience of family members nonetheless. Rather than focus on providing many activities that may appeal to many residents and then spending energy making sure that they are all attending, an activity that might produce a home-like environment from family members’ perspectives is to spend that energy simply being with residents and engaging with them in a meaningful way.

“I feel like there’s not enough going on, there’s not enough activities for these people. Get them out, get them to do stuff. Our activation staff is wonderful when
they’re here but they need more stuff throughout the week, they’re bored, plain bored!” (Staff)

Staff members individually tended to agree with this tension expressed by family members in a conflict with the care approach or with management which they felt did not provide enough opportunities for resident engagement with the environment. The main difference between groups is that staff viewed this as a shortage of resources rather than a facility-based or individual staff-based oversight. A recognition that both groups had was that residents were isolated, bored or even agitated in the environment either based on the amount of recreational activities, the quality/appropriateness of available activities and/or the crowded nature of the environment. Underlying this tension is the view from staff that physical care tasks are not equal in their ability to maintain and enhance personhood than social/psychological tasks. The outcome is that many opportunities for meaningful interactions may be ignored or passed off as less important or meaningful, physical tasks.

Overall, there was a conflict in expectations between family and staff where the former yearned for more thoughtful and meaningful interactions with their loved ones, and the latter wanted more quantity of activities to fend off boredom. From either perspective the approach amounts to a decidedly un- ‘home-like’ experience/atmosphere where residents are either being forced into uncomfortable and individually inappropriate activities or simply do not have enough recreational options. Here we can point to the first example of the need to engage family members more intimately in the care approach to, in this case, better inform staff about which activities or contexts are appropriate for individual residents. A home-like environment should be based on dynamic and processual considerations of where residents are at in terms of their capacity and interests rather than static notions of simply providing activities and spending energy “rushing around and trying to get people to participate in things.”

6.2.2 Contingency as tension (s) in home

*Physical space*

“I know a lot of older nursing homes that look a lot more run down that are more homey than here. Here is more nice but its more institutional. If the goal is
homeness than we’ve achieved that more through the staffing than in the building.” (Staff)

“It’s nice to look at here but its not practical. It’s a lot of running around for us to get residents to activities. It’s beautiful to look at but its not always functional sometimes we can’t fit people in wheelchairs and there’s not enough storage for our activity stuff, they didn’t really build anything for activities so the facility is too big for transporting to activities and too small for storage.” (Staff)

The above quotes representing tensions in the physical environment’s ability to sustain or create a home-like atmosphere. They show that fostering a home-like atmosphere is contingent upon considerations beyond just physical space. The quotes, which are both from staff members, are discussing experiences of the limits to physical or aesthetic aspects of the facilities and their ability to contribute to or foster a home-like environment. This is not achieved through aesthetics alone because home as a concept involves the confluence of holistic, dynamic and relational phenomena that require ongoing and nuanced consideration including and beyond physical characteristics. For the staff members, the physical environment itself limits their ability to provide the type of activities that they feel would best contribute to an engaging environment. For this group, a home-like environment is a functional one in terms of its ability to facilitate meaningful activities for the residents. The aesthetic properties of the building were viewed as secondary to functionality and ability to foster or at least not get in the way of social camaraderie.

**Variability of workers**

“All of the younger staff are not what I’d call cut out for the job. They just don’t have the interest in long term care. I find the young people coming in nowadays they just don’t have the patience. I really think that you can’t just go to school and then go in a facility and start to work.” (Staff)

“You can see quite the difference in the personalities of the younger staff. They don’t give you that opinion that they’re tremendously interested. You can see that they don’t want to be in the role that they’re in, that’s how it almost looks like. They don’t want to be in the role.” (Resident)

A home-like atmosphere was found to be partially contingent on and disturbed by the variability in workers. The individual limits to projecting a home-like atmosphere are displayed in the above quotes by a staff member and resident where, interestingly, they are largely based on the age of the individual staff members providing care. This tension was displayed largely within
the staff group and between residents and staff members, involving those staff groups that are the 
most intimately involved in the care environment (family members generally applauded 
individual staff members for their efforts). It was older or more experienced staff members who 
were most critical of younger staff members and noted that younger staff members were “not 
tremendously interested” or generally “not what [you’d] call cut out for the job” because of a 
perceived lack of patience and life experience that is presumably required to engage thoughtfully 
with the residents. Rather than interpreting this age discrepancy on some age-based quality that 
younger staff somehow intrinsically lack, it is more informative to view this tension as one that 
has a temporal limit. That is, younger and presumably newer staff members are seen as (and feel 
like) ‘strangers’ to other staff members and residents and it takes time to build the trust required 
to form meaningful relationships. Older and longer tenured staff perhaps feel protective of the 
residents while residents interpret the younger staff’s social insecurities as they adjust to their 
new work environment as disinterest – ‘strangers in a strange land’ as is the case for many, if not 
all, new employees and less-experienced individuals. In any case, this tension limited the ability 
of the facilities to project a home-like environment.

**Broader care plan/institutional context**

“I mean we don’t have enough staff and that’s in every place so it’s hard. Our 
seniors deserve more than what they get because of the time that we do have, we 
try our best but it’s just hard with such pressure.” (Staff)

“I feel like a lot of the time the residents want us to sit and talk with them or just 
sit with them but we don’t have time to do that especially the ones that don’t have 
family, they just want company.” (Staff)

“There’s just not enough staff and there’s more and more expectations put on you 
every day and you’re not getting more of anything. I don’t feel like I have enough 
time to do things, like I don’t feel like we are able to give residents the time that 
they deserve you know where we’re running around and I have 50 things to do 
and somebody is crying and I’m trying to prioritize and I’m not able to just sit 
with someone.” (Staff)

The quotes from staff members above describe a perceived institutional/social limit 
placed on them in their ability to provide a home-like environment. It is well documented that 
staff shortages, increasing workloads, and the consequential insufficiency of time are sources of
the deficiency or inadequacy in quality of care (Hall & Kiesners, 2005; Mark, 2002). These experiential tensions show the inadequacy of PCC at a facility level to make up for wider social policy (e.g., worker education, resources, support). The application of PCC language in policy acts to hide this inadequacy from sight and instead shifts the blame to individual workers. The tension here is between the expectations on staff and facilities to provide a high quality of care, and societal provisions granted to them to execute such ideas.

Institutional or dehumanizing care experiences, however, are not solely an outcome of quantitative resource allocation, but also reflect individual values. As Hoagland (1988) and Frank (2004) contend, “caring is a choice we make”. That is, regardless of the systemic context there is an opportunity in the immediate care interactions to enact compassion or, to borrow from a facility that I visited in a previous project, to ‘make every moment matter.’ This is a not a point that is meant to demonize individual workers but rather to emphasize the idea that sheer quantity of staff is not necessarily reflective of facility-based care successes. That is, while more staff can be pivotal in the provision of quality care, increasing staff alone will not resolve the issue of care if the additional staff are providing depersonalizing care based on a stagnant or undertheorized organizational philosophy/approach. Basic, physical care tasks are not essentially different than social-psychological ones. As noted by Weinberg (2006) as well as Day (2013) social/emotional relationships are required to successfully undertake physical care tasks and physical care tasks provide an opportunity to form meaningful relationships rather than necessarily deterring them. This relational understanding serves as a platform to move beyond the false dichotomy between social and physical care tasks.

Overall, it is clear that the tensions expressed in this theme represent an under-theorised approach to home in PCC approaches that espouse ‘home-like’ atmospheres. Viewing home as a relational and dynamic process involving consideration of groups beyond the immediate care dyad provides the conceptual basis to address the above tensions in practice to inform a care approach that leads to real change in quality of life for all groups involved.
6.3 Theme 2: Flexibility (Autonomy and Choice in Care Tasks)

The second theme emerging from the interviews was a general orientation towards flexibility in accomplishing care tasks, allowing residents to choose for themselves what and when care tasks occur. This aligns with PCC’s move away from institutional task-based care approaches and similar to the previous theme, at face-value seems ideal in terms of granting resident’s autonomy and independence that supports their personhood. That is, while the fundamental goal of care for PCC is to maintain and enhance personhood which grants residents autonomy and independence in the care context, the concept has been critiqued for being undertheorized in a number of ways (see Chapter Two) and as such, may not live up to its promise in practice.

Tensions within this theme were again found to play out through and were expressed as collective and contingent experiences of LTC environments informed by PCC. Like the previous theme, tensions arose in its experience from all groups largely based on its application as a unidirectional, static and uncritical exchange of choice that often ended up enhancing incapacitation. Again, supporting personhood as a process involves a more nuanced approach than to simply grant residents full autonomy/independence in a superficial way and more work is required to better understand the relational aspects of the care transaction.

6.3.1 Collectivity as Tension(s) in Flexibility

“The main problem with the approach is that we’ve noticed that if somebody asks my mom a question, she will say no because she doesn’t realize what they’re asking but she will say no every time even if it’s something that she will enjoy. Because they’re instructed to respect their wishes, in my mom’s case it’s not always working for her. We’ve missed a lot of baths because of the responsive rather than proactive approach.” (Family)

“[Staff] would be coming and offering him choices that he wasn’t capable of making and I’ve had to coax them saying there’s no point in asking him if he wants something to drink, you just have to get him something to drink. You need to make choices for him.” (Family)
The main collective tension in this theme as expressed in the above quotes from family members was a conflict between the expectations of staff and family about the choice(s) about when and how to get care tasks done. Family members viewed PCC as a ‘responsive rather than proactive’ approach that neglects to account for the diverse and rich histories of their loved ones when it comes to undertaking care tasks. Specifically, family members were frustrated with the disconnect between an uncritical flexibility in the name of autonomy and the actual needs of their loved ones. The family members in the second quote sums this up concisely by concluding with, “you need to make choices for him,” referring to her loved one. A proactive approach means to strive to make care decisions based on the knowledge of a resident’s context/history alongside their present needs and wishes.

“I know I have to walk because I’m in my chair so much, and you want to go some place and you ring the bell and its ages and ages. Every place is short of staff, there’s three people each day to look after 28 people. That isn’t the worst, they take you to the toilet and you sit down and they say ‘we’ll be back’ and you sit on that hard toilet for ages and ages. That’s the only thing I don’t like about this place: waiting, waiting, waiting.” (Resident)

The act of waiting for basic care tasks to get done and the accompanying feeling of being forgotten was not uncommon amongst the resident respondents as reflected in the above quote. Residents tended to not blame individual staff members for these oversights but rather acknowledged the general lack of resources for staff. While this may be true, an over-emphasis on flexibility in task completion was also viewed by family members as an excuse to not complete basic physical care tasks rather than a way to enhance resident personhood and while it would be unfair to deem the excuse as true, it is clear from residents’ expressions that their personhood or humanity is not enhanced by ignoring their physical needs in service of flexibility. Physical care tasks are not a drain on personhood, but provide a nucleus and an opportunity to build trusting and meaningful relationships that might support the maintenance of personhood. It is important to listen to residents’ feelings about how care is delivered as in this case they denote
a feeling of loneliness and guilt from burdening the staff who are over worked with their basic care needs.

Overall, the critique is that blindly offering choice in the name of independence or autonomy is just as dehumanizing as blindly carrying out quantitatively assessed/justified physical tasks. Neither acknowledges the potential to make meaningful moments in physical tasks and both preclude the need to engage meaningfully with the resident to take their situation, capacity and feelings into account. This is an example of an approach so flexible that it is rendered meaningless in situations where what is best for a resident needs to be decided for her/him in consultation with family members when it was a part of her/his past daily routine.

“A toileting schedule they got to go at that point in time but they’re on this schedule right so you got to turn around and more or less pick and choose, where is [PCC] going to go here, like is the resident going to mess themselves while waiting for this time? Like when you’ve got to go you’ve got to go right? I don’t think [PCC] really falls into that spot at that time. There are some things that need to be done at certain times.” (Staff)

The above quote from a staff member exemplifies a tensions from this group’s perspective regarding the emphasis on flexibility in PCC in that it does not empower staff in the same way as it claims to empower residents. Simply granting full autonomy and independence to residents, while perhaps a step in the right direction, can enhance incapacitation for residents as previously noted (particularly the most vulnerable and frail), and renders both staff and residents passive entities in the care process. Residents’ personhood should be maintained not through simply respecting what they say and wish to do in the immediate moment (although that is certainly a good start), but by respecting and honouring who they are as a human and a citizen by considering the broader interpersonal relationships between family, resident, society and staff in decisions about how, when and what care tasks occur. In sum, personhood, like home in the previous theme, can be better maintained if flexibility in care tasks was viewed as a dynamic social and relational process rather than a one-time, unidirectional exchange.
6.3.2 Contingency as Tension(s) in Flexibility

Variability of Workers

“For some people it’s just a job but a lot of us don’t view it that way. You’re either that way or not regardless of the institutional practice. People who are really structured in their own life struggle a little bit and can be very task-oriented.” (Staff) “Some staff just don’t care they might not even wash the residents and so yeah, I think it’s just laziness. They’re in a rush to get nowhere, they’re not cleaning the residents so like their just more worried about getting more time on their hands afterward but when your resident smells you know, come on, I don’t believe [PCC] comes in for them at all. This stuff is common sense and some people have it and some people don’t right. I go by my own philosophy and I wish some of the other people did the same.” (Staff)

The above quotes reflect an internal group tension where staff members expressed differences on flexibility or ability to maintain the personhood of residents based on their varied individual beliefs and habits that persist into the care environment thereby highlighting the idea that broader societal values and approaches to care that are engrained in and partially shape individual attitudes are more pervasive than internal, institutional philosophies/approaches such as PCC. That is, from the staff perspective, people are not able to change their fundamental beliefs and habits upon entering a LTC facility and thus, staff either have a ‘knack’ for caring or they do not, regardless of facility-based approaches. The staff participants largely believed that PCC and its tenets are simply common sense and, as such, that it is more telling to analyze individual staff members based on their particular philosophy of care than to discuss the facility-based philosophy. This is a moving point at face value (respecting residents’ humanity does not seem ground breaking, after all), however, when considered more carefully it is deeply reflective of an approach (PCC) that, in an effort to centre attention on the resident, has not fully accounted for the personhood of staff enacting it.

The tension between individual staff members can also be understood as a deeper tension between staff and PCC where they are expected to take part in a one-way exchange of personhood granted to residents with little consideration (theoretically) of their own. A core tension experienced by staff when enacting an unthoughtful flexibility in care tasks along with increasing expectations and dwindling resources, is that they become a uniform and ineffective
group whose only role is to transfer a sense of personhood to residents even if it is at odds with their own. Perhaps, this is reflected in a prevailing attitude of, “I go by my own philosophy and I wish some of the other people did the same,” which is a perfectly reasonable response to existing in a philosophy that seems to regard you as a non-entity but expects you to go above and beyond to fulfill the need of others with little systemic or structural support.

**Broader Care Plan/Institutional Context**

“He’s never been incontinent but he’s sitting in that chair all the time and I just feel that wait a minute it means somebody’s not making sure he can get up and go to the bathroom. Had we sat down and gone over his daily routine and what he likes and doesn’t like then a lot of that could have been avoided.” (Family)

“I don’t think it’s a very good program. I suppose it has its place a little bit, but you can’t have someone like my father and ask if he wants to do something, he says no and then walk away. He won’t shower for 3 weeks so it won’t work for some people, it won’t work with my father. I think this person-centred care or whatever is a way for them to say oh well that saves us a lot of time as I know that they have many other patients on the floor to deal with.” (Family)

The above quote from family members depicts the view and critique of the flexibility embedded in PCC as an excuse to not complete tasks in a timely manner or a way for facilities to make up for staff shortages. Certainly, a harsh interpretation, but it seems to ring true when considered next to the tensions in the previous theme where staff felt a building pressure to accomplish tasks but with dwindling resources. This is a practical example of the broader critique of PCC as a state sanctioned band-aid or smokescreen whose language appears novel and thoughtful but whose application is meant to distract or deter attention from the lack of real resources allocated towards LTC, founded on policies based on market-based values (Armstrong and Braedley, 2013). That is, instead of fundamentally changing how older adults are viewed in society and consequently making subsequent reallocations of required resources to support this new and improved perspective, the experiential tension speaks to a superficial adoption of the language of a well-intentioned, but unfinished theory to gloss over the need for more fundamental change. This critique is echoed in the critical gerontology literature on LTC (Edvarsson et al., 2010) as well as in the Dementia Care literature (Innes, et al., 2012) noting that
the adoption of PCC approaches over the past 15-20 years has not resulted in noteworthy increases in the quality of care or quality of life for residents in LTC.

Considering these expressed tensions, an approach that supports an ongoing and dynamic maintenance of personhood rather than a static version focused only on independence is more appropriate in LTC. Opportunities to make meaningful moments exist even in the accomplishment of basic physical tasks and when these tasks are not completed in a timely manner acts to undermine the humanity and consequentially the personhood of residents. Rather than essentially separating the nature of physical versus social care tasks, it would be beneficial to view these relationally as a dynamic interplay of interpersonal and physical meaningful interactions.

6.4 Theme 3: Relationship building

Flexibility and home-like atmospheres are intimately related to the third theme in that the prior two themes or aspects of the environment are pursued with the goal of fostering meaningful relationships. Tensions were expressed as either failed attempts at creating meaningful relationships or a lack of recognition of the importance of building relationships between certain groups. That is, relationships other than/beyond those between staff and residents are also integral parts of a home-like and flexible landscape.

6.4.1 Collectivity as tension(s) in relationship building

“I just wish, if I could, that everybody would have somebody. I visit my mother lots but I see lots that can’t or don’t have somebody because it’s hard when people have to work and yet the staff can’t just go with them, they’ve got to go with everybody. Those are the ones that have trouble adjusting.” (Family)

“I’d be lost without my sons, they’re so good, they visit. It’s a lonely place even though it’s a nice place.” (Resident)

The above quotes reflect the main tension from differing expectations between residents, staff and family members when it comes to relationships in PCC informed LTC environments. The tension emerges from the two recognitions that, first visits and continued relationships with family members are an integral and mediating factor when it comes to the quality of life for
residents and second that if staff have limited time to invest with each resident, it would be prudent to focus a majority of the time beyond basic care tasks to those residents who do not have regular (or any) family visits. This thought stems from a relational approach to personhood where a greater knowledge of each resident’s broader context and situation might be taken up as a way to inform their care. Family members would like to visit more often and residents yearn for more time with their family while staff have little control over the amount of these visits. This is not a tension between groups as much as a further recognition of how important of a role family members play in the residents care outcomes.

“Everybody here seems to be…there’s nobody I can talk to. There are three units on this floor, and I think maybe I’m in the wrong one because I just don’t have anybody to chat with unless my daughter-in-law comes in. I’m set here but maybe someone will come in to talk to after somebody dies.” (Resident)

“ It’s a very in a way solitary life, even though we’re here and intermingle, most people don’t know the next person’s name you know, we’re just waiting for family to come visit.” (Resident)

These thoughts from residents highlight an overlooked or under theorised relationship among residents as causing a tension in their experience. Since the staff are busy and if they do not have family regularly visiting, there is potential for fostering relationships among residents to limit isolation or the feeling of living a ‘solitary life.’ As discussed earlier in this chapter, quality of life is mediated by family visits and relationships, showing family members to be an integral part of the care experience even after a move to LTC. The qualities of the facility and staff are secondary to the number of visits from family members in terms of how residents felt about the environment.

Interactions between residents are fleeting opportunities to form meaningful relationships and residents noted that while many potential opportunities arise by way of daily interactions, the experience is still a solitary one. With a relational justification built into the care approach that recognizes the vast potential that exists in relationships between residents, efforts could be made to situate residents with similar backgrounds or interests together and more time/energy might be spent developing recreational activities or engagements with the physical environment that draws
residents with similar interests and capacities together in a meaningful way. The specific practice-based changes are realistically beyond the scope of this inquiry; however, the expansion of PCC to include the support of relationships beyond that of resident-staff in a relational approach justifies this type of consideration and allow for the potential of relationships to be better realized.

6.4.2 Contingency as tension(s) in relationship building

Physical Space

“It feels so segregated. You don’t see people like you can be here for the whole day and not even see most of the staff. it just seems like an institution. It’s like I have coworkers that I haven’t even met.” (Staff)

The above quote from a staff member can also reasonably be viewed as a tension from the atmosphere theme; however, it specifically mentions the physical environment in terms of its hindrance of meaningful relationships among staff members. This is representative of an experiential tension in PCC where certain relationships are not acknowledged (showing a preference for the care dyad) such as those among staff members, an oversight that was said to be mirrored in the physical environment. The built environment is reflective of the facilities values and if it is not supportive of the necessary relationships to achieving a high quality of care and life for staff (feeling ‘segregated’) it portrays an institutional approach not aligned with a thoughtful care approach.

“There should be more openness so residents can see each other and not just be sitting in their rooms waiting. My mom is seeking contact so lower the walls and have a common space where they’re putting a puzzle together maybe from opposite ends there’s just not enough thought into how to use spaces to bring them together.” (Family)

Relationships amongst residents were seen as being hindered through a lack of opportunities in the physical environment that would bring them together. Family members were concerned that an opportunity for fostering these relationships between residents through including passive activities that they can accomplish together was being overlooked in favor of those forced group activities. This consideration of the capacity of the physical environment to influence relationships, particularly those between residents, is often overlooked in dementia care research and the experiences of all three groups confirm that relation-centred care should involve not only
social relationships and those with family members but also relationships with the physical environment and its influence on the relationships between residents.

**Variability of Workers**

“Every day I come I’m dealing with different staff. It’s hard for me to know on a day to day basis, especially with the staff turnover who to communicate with. It’s really hard to know what the proper lines of communication are and everybody’s busy.” (Family)

The above quote is not a comment on the quality of workers but the scheduling and turnover that does not lend itself to family members getting to know staff members. A literal variability of workers encountered by visiting or calling family members on a day-to-day basis precludes the formation of meaningful relationships that would inform the care approach for a resident. Again, relationships between family members and staff are integral to a successful care approach and if staff is too busy or constantly turning over then it limits the formation of these relationships. While it is experienced on a facility level, the high turnover of staff is not necessarily part of the approach espoused by the facility, but is just as likely a result of structural constraints in the labour force as noted by OLTCA’s 2019 report and cited in Chapter One. Regardless of where this tension originates, the effect it has is to limit the capacity for family members to form relationships with staff members. Further, PCC approaches should justify facility-based practices that actively work against structural constraints that limit their staffing resources to amplify relationships between groups beyond just the care dyad.

**Broader Care Plan/Institutional Context**

“The first interaction we had with my mom and we’re talking about this spot that she doesn’t want to be in we did the whole paperwork but this is when they decided to talk about the medical plan of the end of life. Don’t ever do this on the first day literally the first 15 minutes. Like my mom thinks she’s going to travel the world so it was too much too soon.”(Family)

This final quote is a practical and experiential example of how seemingly mundane moments can act as a reminder of the core institutional nature and feeling of LTC environments, limiting opportunities for relationships to form. Whatever semblance of a feeling of home was established (or potentially could have been) through the first impression was tarnished
immediately through this interaction. The individual relationship with the environment becomes immediately institutional and bleak with these types of untimely and somewhat harsh reminders. Moreover, such an abrupt reminder that this is not home creates a sense of fear that sets the stage for withdrawal and isolation that rob residents of their remaining capacity to engage meaningfully with the world and others in it.

**6.5 Connecting landscapes of long-term care: Advancements and contributions to relational care and place**

In presenting the lived experiences of LTC through a relationally sensitive lens, what the sections 6.2 to 6.4 have highlighted are a number of connections to the literature(s) in Chapter Two and Three that both advance current relational perspectives and contribute new insights or ways to move forward. This section summarizes the connections and contributions to show the ways that experiences noted can be employed to develop theory in both dementia care and geographical gerontology.

**6.5.1 Relational care**

To support a move to relation-centred care the above discussion applied a relational lens to highlight tensions in certain aspects of the person/place transaction in the LTC context. In highlighting the tensions that make up a relational experience of LTC, these findings further the existing literature discussed in Chapter One and Two proposing relation-centred care as a shift from PCC in three main ways. First, on a structural level the findings show the inadequacy of PCC approaches to make up for wider LTC policy (as discussed in Armstrong and Braedley, 2013; Banerjee et al., 2012; Edvardsson et al., 2008). Family members viewed the emphasis on flexibility in care tasks as an excuse for staff to not accomplish certain tasks that they view as integral to quality care, while staff expressed great frustration over the perceived raised expectations placed on them coupled with limited resources. Additionally, staff and residents noted the relative lack of required skill or engagement from younger staff members. What these
experiences show is the impact of staffing levels, expectations from state-sponsored approaches such as PCC, and education of the workforce on facility-based experiences.

Second, on a facility level the experiential findings advance the importance of relationships beyond the care dyad (mainly family) in the quality of life for residents (as discussed in Morhard, Darby and Spira 2013; Nolan et al., 2004). Resident experiences were shown to be highly mediated by family visits and the amount of interaction they had with family members, regardless of their experiences in the facility and with staff. Family members noted that a flexible care approach could be enhanced with greater knowledge of the resident’s individual routine prior to coming into LTC which might be communicated through greater engagement with them (family members). It is clear from the findings that family members play a key role in the experience of LTC and this is a role that need to be nurtured in support of the staff’s ability to interpret resident wishes as well in direct support of the resident’s well-being. This relationship with family in the LTC context was seen to be similarly affected by high staff turnover which undermines the staff’s ability to foster continued relationships with family members.

Finally, in immediate care transactions the experiences show the limitations of the emphasis on independence and choice rather than interdependence - on a reactive rather than proactive approach (as in Daly, 2013; Zimmerman et al., 1997). Expressed mainly as tensions in the flexibility theme, while some residents, staff and family members appreciated the freedom and autonomy granted to residents in immediate care transactions, others noted that it limited staff’s ability to make informed care decisions that would ultimately benefit the residents by justifying decisions based solely on resident autonomy. A greater knowledge of a resident’s history from engagement with family members and a greater trust in staff to take the full context of each individual into account would empower the residents and staff to make each moment matter in the care context. Additionally, staff expressed confusion and frustration as they struggled to attend to residents’ social needs while getting the required physical care tasks accomplished. The staff often did not recognize the relational potential in physical care tasks and
expressed an essential separation of these types of tasks that led to confusion about what was expected of them. This is an experiential tension that aligns with the relational critiques of Frank (2004) and Weinberg (2006) of one-directional care approaches that essentially separate physical from social-psychological tasks.

While most of these tensions aligned with those existing in the dementia care literature from Chapter Two, there were two distinct but overlapping aspects that were not adequately addressed in the literature: the capacity of the physical/built environment to support or undermine personhood and the vast potential for relationships between residents which was shown to be hindered by a lack of consideration for the built environment.

Both residents and family members noted tensions in the frustration of living in a group setting where relationships between occupants are not fostered. While scholarship in dementia care has addressed those important relationships among residents, staff, family members and the systems in which LTC is enacted (as expressed above), there is a relative dearth of scholarship exploring the importance of, and specific ways to foster resident to resident relationships as part of the relational care constellation. What this analysis has shown through the specific tensions expressed is a great opportunity to overcome structural or personal barriers by empowering residents to engage with each other and form new relationships. This was particularly evident in those residents who did not have family members who live close enough (physically or socially) to provide ongoing support and interaction. It was also noted by family members that were frustrated with the provision of forced activities and lack of more passive ones that would give the residents a chance to interact with each other when and where they felt comfortable doing so. Where forced group activities were shown to potentially undermine feelings of comfort or as reminders of institutionalization, passive resident-led activities built into the physical environment present an opportunity for less stressful engagement as well as relationship-building between residents. The barriers to such relationships were shown to be largely developed through
a lack of emphasis on the potential of the built environment to provide or foster such relationships.

PCC has been critiqued for not taking the physical/material world seriously in its contribution to the experience of care which may ultimately stem from the initial thrust of the approach away from the physical aspects of the disease leaving a residual distaste for all things material (Adams, 1996; Lee et al, 2014). While dementia care scholars have made great strides moving beyond PCC in the social-psychological realm, there has been a relative lack of engagement with the deep meaning found in the physical or built environment and the role that it plays in the quality of life of residents. The tensions above show a physical environment that, while aesthetically pleasing is lacking: functionality for the staff; meaningful opportunities to engage with other residents and occupants noted by family members; and a reminder that the facilities are not homes for residents. This lack of engagement with relationships between person and physical place in the dementia care literature is echoed in Fleming et al. (2014) who note that “While there is considerable evidence on the impact of specific design features on problems associated with dementia, the link between the quality of the built environment and quality of life of people with dementia is largely unexplored” (p. 664). Although Chaudhury et al. (2013) and Parker et al. (2004) are notable exceptions, the findings in this project suggest that the relationship between self and place which was noted as lacking in PCC involves consideration of the physical environment and its capacity to affect the experience of LTC beyond what was found in the dementia care literature.

In sum, the tensions highlighted in this dissertation show the integral role that the physical environment has in support or undermining of potential relationships in LTC. While the importance of social relationships within LTC have been thoroughly conceptualized in the dementia care literature, the findings from this project suggest a need to engage more broadly with the potential of the physical aspects of place in LTC to foster social relationships. Additionally, residents and family members noted the vast potential being missed by ignoring the
resident to resident relationships in favor of other parts of the care constellation. They suggested ways that the physical environment might affect such relationships that would empower residents in LTC to continue developing new bonds in a passive and respectful way. While specific, practice-based, suggestions are beyond the scope of this dissertation, theoretically these acknowledgements point to the need for further engagement with specific place-person aspects that were shown to lead to tensions in the experience of LTC.

6.5.2 Relational place

The findings in sections 6.2-6.4 illustrate that place can be understood as a relational concept in the context of LTC, advancing the idea that place-based ideas should be understood relationally in geographical gerontology. In agreement with relational perspectives of place from Cummin et al. (2007), Cutchin (2005), Milligan and Wiles (2010) and Wiles (2005) discussed in Chapter Three, these findings show that place in the LTC context is experienced as a dynamic multi-scalar process rather than as a static and isolated location holding intrinsic meaning. Specifically, the experiences of LTC were shown to be simultaneously bound to structural, facility-based and immediate contexts that reflect and affect both social-psychological and physical aspects of the facilities.

As discussed in the previous section, facility-based experiences of care were shown to be influenced by structural factors such as staffing levels, funding levels, LTC work education and provincial expectations. The staff felt an exceptional burden from provincial quality of care expectations coupled with limited resources. Underlying this broad depiction is the changing face of LTC as discussed in Chapter One, where residents are entering LTC with more complex care needs than ever before which is felt directly by the staff struggling to maintain a level of care with limited resources. Family members recognized this staffing issue and were frustrated with what they perceived as an approach to care that provides staff with an excuse to not get necessary tasks done, while residents experienced these structural limitations as the feeling of constantly waiting due to a lack of staff. LTC facilities do not exist in a vacuum and much of the tensions that make up the experience of LTC relate directly or indirectly to structural inadequacies.
The experiences noted were also related to facility-based place features and individual context. Staff expressed tensions about the built environment. The built environment was viewed as more aesthetically pleasing than functional in its ability to enable the staff to provide the type of care that was expected. Staff noted the disconnect between how the facility looks and how it feels, recognizing that home-like in the LTC context involves considerations beyond how it looks. Family members similarly expressed tensions about an uninspiring physical environment, a lack of meaningful activities as well as their lack of social integration that amounted to a lack of knowledge about the residents that would help the staff gain important insight about the residents. Residents expressed a yearning for more visits from family members and ultimately the desire to go home.

These tensions in the resident experiences were shown to be rooted partially in a lack of meaningful activities aligning with the findings of Cutchin, Owen and Chang (2003) who found that for older adults living in an assisted living facility “meaningful activity in place is central to overcoming disruptions in the person–place relationship [and] involvement in activities of place is a significant predictor of at homeness.” (p. 240). This brings attention to the ways that these tensions imply a temporal aspect to the meaning of place in the LTC context. That is, they expose the potential for positive change by highlighting where it is needed. These findings show that facility-based physical features, social relationships and activities provided all play a role in the experience of LTC. In the LTC context, the findings show that the physical/built environment has potential, just as the social environment, to cause agitation or fulfillment for its inhabitants and experiences of this may vary between and within groups (as discussed in Chaudhurry et al., 2013; Fleming et al., 2014). Further, the differing tensions between groups shows that the same place is experienced variably between people based on the particular context. While it is clear from the findings that, aligning with scholars such as Wiles 2005 and Cutchin 2005, LTC experiences should be understood as relationally constructed, it is these varying conceptions of home in the
LTC context that are underexplored in geographical gerontology and as such, make up the original contribution to the field from this dissertation.

Beyond the above advancement of a relational understanding of place in the LTC context, the findings contribute an original perspective of home as a concept that has not been adequately theorized in geographical gerontology as the LTC context has seen little attention in this field as noted in Chapter Three and in Skinner et al., 2018. By considering instances and expressions of how the experience of LTC is not reminiscent of home or home-like, the findings imply the contrasting information about what home is for each group involved. None of the residents, staff or family view the facility as their home but this context is rich with information about home as a concept beyond a location as residents reflect on memories of their real or imagined home of the past and the two other groups reflect on how the institutional directive of home-like is not achieved from their perspective. Just as the nature of home in the household dwelling is altered in the context of long-term home care (Dyck et al., 2005) so to is the nature of home reconsidered when the concept of home is applied to institutional settings which by their very nature are places set in contrast to the home.

The findings show that staff experienced tensions in the home-like theme when they perceived the environment to be more aesthetically pleasing than functional in terms of its support of their ability to provide meaningful activities. Of course, the staff in LTC do not live in the facility but their goal is to provide a home-like experience for the residents so they impart their perception of home where they are empowered to do so. For the staff, then home in a physical sense is experienced as a functional place, beyond its appearance or location. Additionally, just as the lack of functionality in the physical environment limits the staff’s ability to foster a sense of home, as does the structural context. That is, while staff were frustrated about the lack of functionality that limited their ability to recreate home for the residents, they did not feel that the resources allocated to LTC were sufficient to support a sense of home for themselves. Tensions in a sense of home for staff were multiscalar, based in the immediate
physical functionality and simultaneously in the perceived lack of structural support. Structural and functional aspects, then, make up the staff’s experience of home in LTC.

Findings from the family participants show that their particular tensions around home in LTC stem from a lack of opportunities for meaningful interaction in both the social and physical environment as well as among all three participant groups. For family members in LTC, home is based in ongoing interactions with familiar people that have potential to foster a sense of place in the face of relocation. This is shown in their suggestion to include passive interactive activities in the physical environment to support development of relationships among residents in contrast to the forced group activities which they viewed as potentially inappropriate or institutional. For family, a home-like environment presents opportunities for engagement but does not imply pressure to take part – it is passive and familiar where familiarity breeds comfort to form new relationships. The concept of home as familiarity suggests an ongoing and dynamic capacity to build new connections even in the context of LTC. Similar to the staff experiences, family members noted their own lack of familiarity with the staff due to high turnover. Family members were frustrated that they did not see the same staff members each time they visited, again presenting a structural limitation to a sense of home.

The resident experience of home in LTC is perhaps best understood in terms of Milligan and Wiles’ 2010 discussion of distance in the care context as both proximal and social-psychological. Residents unsurprisingly yearned to be physically back in their past households. In the residential LTC context and in contrast to homecare, that is not a possibility and, as such the proximal aspect of home cannot be fully satisfied – they will never again be in that physical household that they imagine as their home. Home for residents in LTC, then, is a relative term rather than strictly a location that can be approached but not fully realized in the support of both ongoing social relationships that serve as past reminders (mainly family as shown in the findings above) along with new relationships with both staff and other residents. Relocation to a group living setting such as LTC presents both challenges and opportunities in the realization of a sense
of home. While the former are well documented and mainly based on relocation, physical distance and institutional group living arrangements, the latter lie in the new potential relationships with staff and other residents that are ignored in the strictly proximal view of distance or the perspective of home as strictly a household/location. That is, ignoring the dynamic and processual aspects of home in this context amounts to missing out on the possibilities for supporting a relative and relational sense of home and ultimately sense of place for residents.

As noted above, staff and family participants showed the various possibilities in LTC to shrink the social-psychological distance from home while residents showed that their experience of home is not strictly based on physical distance. This relative and relational distance aligns with Kitwood’s ideas around relative ill/well-being in dementia care discussed in Chapter Two where in the face of a chronic illness objective health is not an option, the heightened consideration of other aspects of well-being can support a relatively high quality of life. Overall, the findings contribute a conception of home in LTC as functional, familiar, and relative construct from the perspective of staff, family and residents.
Chapter 7 Relational place and long-term care: Concluding thoughts and reflections

The aim of this dissertation was to provide a relational, place-sensitive perspective of LTC experiences in facilities espousing PCC based on the experiential tensions that act to ground some conceptual tensions noted in the surrounding literature. These experiences both construct and are viewed through a landscape of LTC framework. The analysis also exposed how and why we should continue the project set out by Kitwood (1997) rather than accepting his unfinished project as gospel. In doing so, the dissertation has aligned two distinct fields (Dementia Care and Geographical Gerontology) through a shared espousal of relationality as the conceptual way forward and a shared interest in informing an approach to LTC that is better suited to the lived experiences of people with dementia.

The final chapter serves to both elucidate and reflect upon the objectives of this inquiry in terms of how they have been addressed, the significance of the contributions in pursuance of each objective, and the limitations embedded in and emerging from the approach taken. Further, additional articulations about both how I have been moved personally and the possibilities and recommendations for future research building on or arising from the present inquiry will be presented. Specifically, the chapter is structured within the conceptual, methodological, and practical objectives that shaped the project where each is addressed in terms of how the research contributed to a particular aspect, the limitations of the research and consequential suggestions for future research.

7.1 Conceptual advancements

The core concepts of care, personhood and home were reimagined as relational, dynamic and processual aspects of the LTC experience in an effort to expand PCC from within and include such understanding of the experience into a novel ‘landscapes of LTC’ framework. The following sections synthesize the specific conceptual expansions and the groundwork paved in pursuit of a landscape of LTC. Conceptual limitations and recommendations for future research follow.
7.1.1 Care, personhood and place (home) reconsidered

**Home**

An interrogation of the concept of home in PCC relates to how it is perceived as an integral but undertheorized part of maintaining personhood so while there is a separate consideration of personhood broadly, this reimagining of home is essentially an internal expansion of personhood itself. It is considered distinctly due to its clear relevancy to geographical thinking where place is a central concern. The main expansion of home based on the tensions found experientially arose from within the ‘atmosphere’ theme. Participants noted that a ‘home-like’ atmosphere is not accomplished from considerations solely of the physical/material environment. That is, how the facility looks is not the same as how it feels and building a house or cottage-like structure does not necessarily equate to a home-like environment.

Specifically noted were the needs to include a consideration of appropriate recreational activities that are better suited to individual capabilities, as well as a deeper consideration of the integral role that family members play in the construction of a home-like environment. Such a depiction of the environment might lead to an increased capacity for staff to provide more individually focused activities. Family members play a mediating role in the experience of LTC and it would benefit any approach to care to fundamentally acknowledge this role by engraining family members in the ‘atmosphere’ or home-like aspect and conceptions of home in general in a way that might facilitate a more efficient and effective use of time.

Having focused on direct family members throughout this dissertation, it is important to note and acknowledge that close friends and other actors such as volunteers might play the role of informal carers for a person in LTC. As a result, focusing on the experiences of non-family carers is an interesting and important direction for further research on LTC.

**Care**

Care is the functional piece within PCC as its particular conceptualization shapes how, when and by whom the approach is (or ought to be) enacted. Tensions arising from an individual-
based, uni-directional and static conception of care arose in all three themes as it is a concept that runs through all aspects of the experience.

In the home-like atmosphere theme tensions around care arose from a fundamental separation of physical and social care tasks such that there was not enough time to carry out those essentially social tasks that were said to directly amount to meaningful relationships but upon reflection it was found that meaningful relationships can exist/emerge outside of specifically socially designated tasks. A relational expansion in care recognizes the idea that every moment matters in the care context and there is great potential even in mundane, physical care tasks to form meaningful relationships. While there are structural issues that unquestionably play a role in limiting the resources available for care, a facility-wide approach that focuses on the possibilities in mundane or basic physical tasks works against such structural and resource-based limitations.

Relationships are not formed solely out of interactions that are specifically designed to nurture them. They emerge also through prolonged interactions of any nature where trust and comfort have been fostered. Physical care tasks such as toileting are not in themselves celebrated as particularly social occasions, but they present opportunities to complete the task in a timely and thoughtful way which, according to residents, can go a long way in increasing their quality of life. Spending meaningful time with residents that does not involve care tasks is certainly ideal but within the structural context that does not allow for ample down time for staff it is imperative that the care approach supports an expanded approach to recognize the opportunities in everyday, physical care tasks to make those moments matter.

In the flexibility theme it was found that while some amount of flexibility in care tasks is helpful to move away from a fundamentally task-based approach, in the case of PCC, such an emphasis can leave staff impotent to make any informed and timely decisions. The analysis of flexibility also highlighted the incapacities of residents, particularly those who would benefit from a proactive approach as they are limited physically and socially in their ability to meaningfully make care decisions for themselves. Such a proactive approach was found to be
supported in the relationship building theme where actively fostering relationships outside of/beyond the care dyad can prove helpful in providing the information required and relieving some pressure from staff in the care exchange. That is, an expansion of the care experience ought to include recognition of staff to family and resident to resident relationships which are crucial to develop for acquiring essential contextual information for immediate care decisions and more generally. The analysis ultimately shows that quality care is an active and dynamic engagement involving support from groups outside of staff and residents and beyond passively allowing for choice.

**Personhood**

Also arising in all of the themes were tensions as manifestations of a static and stale conception of personhood – the stated goal of PCC. A relational perspective posits an expansion towards a processual and emergent quality rather than one-off, impersonal allowances of choice in a one-way ‘personhood exchange.’ Broadly, the significance of this process is a suggested de-centering of the resident as the sole member on an existential plane that is disembodied and essentially static, where they passively wait to be granted humanity in the form of independence. Maintaining personhood as a process involves ongoing, proactive and informed decisions in the care context that require knowledge of individual historical and present context.

Residents expressed feelings of solitude, loneliness and longing that are not conducive to or representative of an enhancement of their personhood and in fact are known to lead to withdrawal and further isolation. This was not unexpected given the institutional nature of LTC, but it does imply that PCC in its current formulation is not a solution to any of these fundamental issues as it is often presented as being. As both concepts of home and care are internal and functional processes employed to achieve this overarching goal, their critiques and expansions are embedded in those of personhood and there is a considerable amount of conceptual overlap. The expansion of personhood as a concept that denotes the ultimate goal of LTC then, is of course
deeply intertwined with that of its functional contents and might be viewed as an outcome of their expansion.

A resident noted, “I’d be lost without my sons, they’re so good, they visit…it’s a lonely place even though it’s a nice place,” which is representative of the expansion needed in our conception of personhood in the atmosphere theme and mirrors the conception of home discussed previously. The residents looked forward mainly to family visits as they recognized that staff is too busy to take them out and the recreational activities are either not appropriate for them or simply not enjoyable. A home-like environment which is said to enhance or maintain personhood, according to the residents is one that includes or at least considers family members as essential factors. The lack of appropriate activities is due to a lack of individual activation which leads to either not enough opportunities or an abundance of inappropriate ones. To mitigate this, it is suggested that those residents who do not have regular family visits be the focus of activity priorities. More importantly though is an expansion of personhood and particularly the idea of home as a personhood conduit to include family members as fundamental considerations as they, more than any physical alterations, are the reminders of home. To maintain personhood is to support ongoing relationships among family members to facilitate the comfort required to form new relationships and relieve pressure on staff to provide generic and stale activities.

Again, following from an earlier conceptual expansion, this time from that of care, in seeking to maintain and enhance personhood, flexibility in the pursuit of autonomy and independence for residents was not found to be sufficient in the pursuit of empowerment or bestowing of a human status. In environments informed by PCC, residents expressed feelings of hopelessness in waiting for basic care tasks to be accomplished while staff expressed a lack of resources to spend meaningful time with residents and family members expressed a frustration with a reactive rather than proactive care approach. Instead of supporting a series of uninformed, one-way and one-off allowances of independence, it is suggested that the pursuit of personhood is better supported through enabling staff to engage with residents and family members to better
inform individual capacities and lifestyle contexts. That is, a relational focused care approach, while still focusing on the needs of residents, takes into account relevant information beyond what the resident is saying at that moment and places it in the context of the resident’s full history and present capacities. This is not to negate the present abilities of the resident but to acknowledge them in their relational context as full and complex individuals.

Such knowledge of the resident’s past and present capabilities and lifestyle facilitates and supports their empowerment as this allows individualized and appropriate supports to be made available. A resident’s humanity is not maintained by haphazardly assuming independence and autonomy as many residents require a proactive approach to allow them to make decisions based on their continuing capacities in tandem with their past life context. This often means making decisions that are best for them based on information gathered from family members and building a meaningful relationship with both groups. Acknowledging family members as key players in the care approach and justifying their intimate involvement would go a long way to accessing the type of knowledge that supports resident empowerment as this group seems to be an untapped resource in current conceptions of PCC. Further, resident to resident relationships are not recognized as part of PCC as its maintenance of personhood hinges solely on the care dyad. Particularly for those residents who do not have family regularly visiting, fostering these relationships among residents takes some pressure off of staff and presents an opportunity to address the loneliness expressed by residents in this research. They are surrounded by other residents but not currently encouraged to meaningfully engage with each other. Other residents along with family members ought to be more engrained in a conception of personhood as an expansion of PCC in LTC environments.

7.1.2 An emergent ‘landscape of LTC’

As a processual, emergent structure, the landscapes of LTC framework is simultaneously both an outcome and origin of the critical expansion of the above concepts. That is, the construction of or contribution to a landscape of LTC was undertaken through engagement with
these core concepts along with empirically emergent themes representing an experience of place (PCC informed LTC facilities) that was developed through it while also acting as its building blocks. It is shaped by the particular experiences of LTC gathered empirically through the research reflecting the ‘novel’ aspect of the approach which is based on the inclusion and consideration of a group (older adults living in LTC) which has not seen adequate engagement in the field of geographical gerontology to date. The framework was adopted from the homecare setting and its development is through engagement with experiences in the LTC context.

The experiences were distilled into three emergent experiential themes of home-like, flexibility in the care approach and supporting relationship-building which provide the fundamental base within this framework. Within each emergent experiential theme there were tensions identified which were viewed as manifestations of conceptual weak spots to focus on for an expansion of the salient core concepts noted earlier. These core concepts then make up the conceptual building blocks of a new framework to bolster the experiential themes. Together these experiential and conceptual aspects form a perspective and understanding of the experience of LTC that is situated in qualitative empirical information and enacted through a critical understanding of core concepts that guide/justify the behaviour of the groups involved.

The significance of this contribution is that it advances a relational understanding of place to in the LTC context to provide a starting point from which to conduct further research with the vulnerable and substantial group of older persons living with dementia, and in contested and intimate LTC environments.

7.2 Methodological contributions

In an effort to address the aim of this dissertation and support the conceptual and practical goals, the methodological objective of this dissertation was to collect empirical qualitative data from staff, family and residents in three LTC facilities espousing PCC-based approaches and elucidate the lived experience in the facilities. The methodology was to be further refined with a focus on the tensions portrayed in experiences as these represent the gaps or points
of possible expansion of PCC to be discussed in terms of the conceptual critiques and consequential ways forward. Within this general methodological objective was an opportunity to create a discursive space to hear the voices of residents, particularly those living with dementia, in their own representation of the experience of PCC. These objectives were ultimately satisfied through interviews with 22 staff members, 18 family members and 15 residents in three LTC facilities within the South East LHIN boundaries. The interviews were supported and informed through time spent passively observing in each facility which also served to provide context in the form of my own perspective that is also reflected in my interpretations of the results. A humanistic philosophical orientation that employed interpersonal, experiential and empathetic epistemological approaches guided by underlying personal senses of wonder, humility and reflexivity were applied to the data in an effort to access and present a lived emplacement or experience as the object of inquiry.

7.3 Practical/community-based contributions

The practical/community-based objective supporting the broad aim to expand PCC was to work with participating LTC facilities to develop, carry out and disseminate the project in a way that supports their internal goals and those of the community at large. This community-based approach ensured that the research was done with rather than for participating facilities in a mutually beneficial partnership. Management and staff in each facility were consulted throughout the project and facilitated much of the data collection. This maintained our trusting relationship, the mutually beneficial nature of which was displayed clearly in my participation as a community representative in an accreditation process meeting at one of the facilities.

A facility-based presentation of information not only promotes internal growth but also the sharing of information amongst facilities where they are brought together to learn from each other in a forum that would not otherwise have happened. In that sense, the research partnerships formed throughout this project fostered community-based partnerships among the facilities providing a new knowledge translation opportunity. This aspect of the dissemination likewise
strengthened the present inquiry, grounding it in a practical application alongside its academic and conceptual merits. Facility staff and management not only facilitated the research process, but in doing so they implicitly justified the aim of the project. That is, as operators and workers in LTC, the fact that they found the research meaningful and worth spending their time as participants is a practical justification of the research.

Further research in LTC should continue to integrate projects with the needs and expertise of the people who work and live in LTC facilities. This grounds the conceptual efforts in practice and ensures that the goals of research align with those of workers in the field.

7.4 Long-term care policy implications

The experiences of LTC examined suggest some policy initiatives that seem to directly affect the quality of life for the staff, family and residents involved in this research. However, as this is a facility-level inquiry that does not employ a critical structural lens, these implications arise from surface-level observations and do not diverge in any great measure from those suggestions that can be found in the OLTCA (2019) report as described in Chapter One. The first implication is simply the need for higher staffing levels in LTC. Staff expressed feeling overwhelmed with the heightened expectations and pressures from both the proliferation of PCC as an approach and the increasingly complex LTC resident population. These heightened expectations coupled with a perceived lack of support in the form of higher staffing levels led to much frustration in their inability to provide the level of care that they wished to provide.

Additionally, both staff and residents noticed that newer and younger staff members were less interested and capable than those more experienced staff members. This suggests the need to reform how various roles in LTC are provided education and training to catch up to the changing demographic of residents. The OLTCA report notes that, “in a 2018 survey of Ontario’s long-term care homes, 80% of respondents said they had difficulty filling shifts, and 90% experienced challenges recruiting staff…The [staffing]situation has reached a tipping point.” (pg. 8). The report suggests that a provincial staffing strategy is needed to recruit younger workers and
international workers, enhance training programs and provide grants to workers seeking education. These suggestions were echoed in the experiences elicited in this dissertation suggesting that the staffing situation has indeed reached a tipping point and as more LTC homes are needed it will only get worse. While facility-based care approaches should continue to develop, their implementation is limited by dwindling staffing levels and quality of education.

7.5 Limitations and suggestions for future research

Conceptual/Theoretical

As with any conceptual approach or lens, in highlighting certain experiences with a particular orientation the embedded limitation is a recognition of what information or form of information was consequently left out. While new and informative perspectives on the experience of LTC were gleaned through the lens articulated throughout the dissertation it is suggested that researchers continue to explore new conceptual pathways to ultimately led to a more robust framework for understanding the experience of LTC.

Relating to the field of geographical gerontology, having presented these experiences as projections through a broadly humanist and relational world view, moving forward it would be instructive to apply different theoretical perspectives as they continue to (re)shape how we view the world and the nature of our access to it. With this in mind, a recent theoretical advancement in geographical thinking and the social sciences founded on a post-humanist theoretical orientation, alerts us to an ontological understanding that is more than/beyond representational (Andrews, 2014; Andrews and Grenier, 2015; Cadman, 2009; Pile, 2010). That is, it seeks to highlight or animate not what was explicitly expressed about an experience, but rather the pre-conscious affective conditions through which expressions of emotion and experience are rendered: the pre-social foundations of the expressions themselves. From this more than representational perspective, it is argued, as Herron (2018) notes, that, “before we can examine the feelings and attachments that we have to, and in, particular places, these feelings are already in the process of forming.” (pg. 177) The main challenge then, is to observe and communicate these less-than-
fully-conscious happenings or animate not what has happened but how the conditions that constitute such actions came to be. This is a moving conceptual approach particularly for research involving people living with dementia who may lack the capacity to express or recollect events or feelings but will nonetheless express an experience preconsciously through affective encounters. Certainly, an application of this novel conceptual approach or methodological style to the experiences (whether conscious or less-than-conscious) of LTC would enhance our understanding of such experiences beyond this dissertation.

As it relates to the critical gerontological/dementia care literature, this dissertation did not engage directly with concepts of embodiment or, consequently, relational citizenship in dementia care as elaborated in Chapter Two as developed in critical gerontology scholarship (see Davis, 2004; Downs, 2013; Kontos and Martin, 2013; Kontos et al., 2016; Martin et al., 2013; Twigg and Buse, 2013). Employing an embodied approach to understanding people living with dementia and dementia care provides a conceptual way to move beyond PCC approaches and gain a greater understanding in two main ways. First, the ways that bodies are sites of individual expressions of identity, autonomy and feelings often contained in pre-reflective and seemingly mundane acts of and utterances in response to everyday stimuli such as dress (Twigg and Buse, 2013), personal care and bathing (Ward and Campbell, 2013) that serve to support or undermine identity and autonomy and the ways that we understand bodies and embodied expressions as a reflection of wider cultural imaginations and structural contexts (Kontos et al., 2016). This is a particularly important development for people living with dementia who are often assumed to have lost the potential for agency due to cognitive decline. An embodied approach, in its sensitivity to the pre-conscious capacity of the body to elicit meaning and agency, recognizes the ways that people living with dementia have retained their agency and ability to communicate with the world in a way that problematizes cultural and political assumptions of incapacitation. As such, further research with people living with dementia in LTC should engage with the ways that selfhood is
embodied and the ways that this is undermined through negative political, social and economic policy.

Another promising conceptual lens that the dissertation did not engage directly with is critical structural theory such as the feminist political economy approach in Chapter One (see Armstrong and Braedley, 2013; Bhattacharyya 2009; Peterson and Hugan, 2001). While the dissertation included structural components as part of the relational context of LTC, there was not a broader critical lens applied to the findings to show how the experiences reflected aspects of wider socio-economic structures or prevailing attitudes and beliefs. There is great potential to provide a deeper understanding of LTC experiences with respect to how they are situated within an inequitable systemic context acting beyond the facility-level perspective. This is shown in the dissertation in the many experiential references to a lack of resources for the LTC workforce along with the corresponding impractical expectations set for staff which both beg the question of within what systemic context was this justified or normalized? There are clearly wider limits placed on the implementation of PCC at the facility and individual level and it is suggested that further research continue Armstrong and Braedley’s 2013 work to critically investigate the society-wide structures through which such limits are realized.

Methodological

While the methodological approach was largely successful, there are a number of limitations to be addressed that might aid future research. First, as a relatively inexperienced interviewer it was difficult to meaningfully engage with participants, particularly with the resident group. Although much information was gleaned from this group, a number of the interviews were cut short as I was not able to guide the conversations to the extent that a more experienced interviewer might. The resident group required a certain level of comfort and experience to meaningfully engage with them in a prolonged manner and the results would have benefited from a researcher who possesses these skills. Second, the observation phase would have benefited from taking the form of a more pronounced role such as that of a volunteer. Assuming a
passive ‘fly on the wall’ position granted me the freedom to explore the facilities in my own time and take in the surroundings as they occurred; however, it was often confusing for staff and residents which possibly changed how they went about their daily tasks. Taking on a more specified role where I could embed myself in the environment more seamlessly would likely have amounted to a more fulsome perspective. Last, although the observations took place in a range of locations in each facility at various times, they generally occurred in the early afternoon. A wider range of timings for observations would again have garnered a more robust perspective as experience is not temporally homogeneous and there are various staffing levels based on shift timing.

Based on the limitations and lessons learned and as noted in the previous conceptual section, it is suggested that researchers continue to develop the landscapes of LTC framework through engagement: with different groups involved in the experience such as volunteers, administration, board members and LTC policy makers; other facilities in a range of locations beyond the South East LHIN espousing approaches that are distinct from PCC; and employing an array of appropriate methodological designs featuring extended observation such as autoethnography (Liggins, Kearns and Adams, 2013) and non-representational ethnography (Vannini, 2015) as well as methods such as photovoice (Wiersma, 2011) to better attend to the resident perspective.

7.6 Original contributions

Notwithstanding the limitations and suggestions for future research, this dissertation makes a number of contributions beyond its furthering of a relational understanding of place and care in the LTC context. Dementia care scholarship has made great strides to extend PCC to more relational approaches that consider care as an interdependent and reciprocal concept as well as considering not only the care dyad but also family members as key components of the relational transaction. What this dissertation highlights by employing a place-sensitive framework are two relational components of the LTC context that have been underexplored in dementia care studies:
the potential in building relationships between residents and the potential of the physical/built aspect of the LTC environment to foster new meaningful relationships. The findings in Chapter 6 showed where tensions arose through a lack of consideration of these two relational components that offer a new expansion of PCC. This contribution responds to the call in dementia care research to consider the transactions between place and self in the LTC context by highlighting those transactions that have not been adequately explored in relational approaches to care.

In geographical gerontology, LTC is a context that is relatively unexplored and the contribution this dissertation makes to this scholarship is to draw directly from these unexplored experiences of the staff, family and residents in LTC facilities to add to our understanding of the concept of home as they conceive of it. Specifically, the findings contribute a conception of home in LTC from the perspective of staff, family and residents as a functional, familiar, and relative construct. This finding adds to the vast geographical scholarship that considers home as a dynamic process beyond the household.

7.7 Personal reflections: PCC reconsidered

Upon reflection of these experiential findings, it seems that the idea of care being ‘centred’ on any particular group is problematic. Residents and those living with dementia exist on the same existential and human plane as others in the care relationship. To conceptualize them as sole occupiers of the ‘center’ is to further an essentialist view of their incapacity, only with softer language than a biomedical approach may employ. On this semantic point, I would suggest that to move beyond PCC it is necessary to adjust the nomenclature (and its subsequent theoretical implication) in a direction away from any kind of static ‘centering’ and towards a level plane of relationships among humans, all equally deserving of care and a quality of life because of that status. Caring should ideally not require individuals to go above and beyond in spite of structural or facility-based conditions, but rather it should be embedded in a relational ethos where caring for people who require care for whatever reason is simply what we ought to be doing. Perhaps the fact that staff members of LTC facilities feel the need to internally implement
and defend ostensibly moral philosophies about the continued humanity of their vulnerable occupants says more about our values as a society than it does about the specific theories espoused. That is, why do we need to constantly remind each other upon entry to LTC facilities that older adults and those living with dementia are still human and should be treated as such? Until this fundamental societal limit is breached, it is worth following Kitwood’s advice to continue building and expanding upon such internal theories and approaches based on their lived experience and arising from engagement with a multiplicity of disciplines and research approaches as the successes may ultimately leak into or, until a change occurs, work against broader structures justifying a denial of the humanity and/or personhood of vulnerable populations.
Bibliography


Appendix I General Research Ethics Board Approval
August 16, 2017

Mr. Kyle Plumb  
Ph.D. Candidate  
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Queen's University  
Kingston, ON, K7L 3N6

GREB Ref #: GGEOPL-228-17; TRAQ # 6021617  
Title: "GGEOPL-228-17 Placing Institutional Dementia Care"

Dear Mr. Plumb:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GGEOPL-228-17 Placing Institutional Dementia Care" for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (405.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at http://www.queensu.ca/traq/sitorn.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Annual Renewal/Closure Form for Cleared Studies"). Please note that when your research project is completed, you need to submit an Annual Renewal/Closure Form in Romeo/traq indicating that the project is 'completed' so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form at http://www.queensu.ca/traq/sitorn.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Adverse Event Form"). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at http://www.queensu.ca/traq/sitorn.html; click on "Events"; under "Create New Event" click on "General Research Ethics Board Request for the Amendment of Approved Studies". Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Sincerely,

Joan Stevenson, Ph.D.  
Interim Chair  
General Research Ethics Board

c:  
Dr. Mark Rosenberg, Supervisor  
Dr. Heather Castleden, Chair, Unit REB  
Ms. Joan Knox, Dept. Admin.
Appendix II Letter of Information / Consent for Family, Staff and Management

A Study about long-term care for people living with dementia and their care partner

Principal Investigator:
Kyle Plumb PhD Candidate
of Geography and Planning
Queen’s University
Kingston, Ontario, Canada
(613) 449-2140
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Supervisor: Dr Mark Rosenberg
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Purpose of the Study:
As a Staff member, Management member or family member connected to this care facility, you are invited to take part in this study on relationships between an approach or philosophy of dementia care and the lived experience in terms of physical, social and psychological outcomes. I want to gain an in depth understanding of how different approaches to long-term dementia care are played out in their lived experience from the perspective of those who are affected by it directly or indirectly through a loved one.

What does Your Participation Include?
You will be asked to participate in a 20 to 30 minute interview with me to help me understand from your perspective the lived experiences that amount from specific approaches to dementia care. With your permission I will take handwritten notes throughout the interview and it will be audio recorded. I will be asking you simple questions about your experiences and the experiences of your loved one as they relate to the long-term care facility and the approaches that guide its decision-making. This interview may take place in any location and at your convenience.

Are there any risks to doing this study?
There are no known or anticipated physical, psychological, economic, or social risks associated with the interviews or the study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study?
Although there are no direct/immediate benefits to taking part in this study, in general the opportunity to have a discursive space for participant voices to be heard in their representation can be used to improve the living and working conditions in residential care facilities and communities moving forward. This project will provide an important, spatially sensitive perspective on residential care environments that will help to guide how we should best address the needs of this particularly vulnerable group and their care partners from their own standpoint.

Confidentiality
You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell.

Digital records from the interview will be saved to encrypted memory devices. When the interview is over, the original digital records will be copied to anonymous files with only a record number to identify each person and their comments. The original encrypted file will then be stored in a locked cabinet and only used again should the anonymous file be damaged or destroyed to create a new anonymous file. Five years after the completion of the project, the original encrypted files will be destroyed. Material from the interview may be published in community reports, professional journals or presented at scientific conferences, but any such presentations will be of general findings, any quotes will contain nothing that can identify the person who made the comment and will never breach individual confidentiality.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can stop (withdraw), from the interview for whatever reason, even after signing the consent form or part-way through the study or up until approximately May 2019 when I expect to be submitting my Dissertation. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results

I expect to have this study completed by approximately May 2019. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study: If you have questions or need more information about the study itself, please contact me or my supervisor at:

Kyle Plumb
4kbp@queensu.ca
(613) 449-2140

Mark Rosenberg
mark.rosenberg@queensu.ca

This study has been reviewed by the Queens University Research Ethics Board and received ethics clearance. If you have any ethics concerns please contact the General Research Ethics Board (GREB) at 1-844-535-2988 (Toll free in North America) or chair at GREB@queensu.ca.

CONSENT

- I have read the information presented in the information letter about a study being conducted by Kyle Plumb at Queen’s University.
• I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
• I understand that if I agree to participate in this study, I may withdraw from the study at any time.
• I have been given a copy of this form.
• I agree to participate in the study.

Signature: ______________________________________
Date: ______________

Name of Participant (Printed) ___________________________

- Yes, I would like to receive a summary of the study’s results.  
  Please send them to me at this email address ___________________________
  Or to this mailing address: ___________________________
  ___________________________________________________
Appendix III Consent/Assent for Residents

You are invited to be a part of a study from Queen’s University that aims to better understand what it is like to live in a care facility from your own perspective. As we are trying to add to the discussion about improving living conditions for older adults, it is important to us that we hear from people who are actually living in long-term care facilities so we are asking that you participate in a short interview to tell us about your experiences.

Who are we?

My name is Kyle Plumb and I am a PhD Student at Queen’s University. I work in the Department of Geography at Queen’s University. This study is a partnership between the facility that you live in and myself so if you have any concerns you can contact me by phone at (613)449-2140, by email at 4kbp@queensu.ca or you can speak with someone in the facility.

Why are we meeting with you?

We want to tell you about a study that involves people living in this place/facility like yourself. We want to see if you would like to be in this study too.

Why are we doing this study?

We want to find out what it is like to live here and other similar care facilities to help understand what you think about it.

What will happen to you if you are in the study?

If you decide to take part in this study I will ask you to have a conversation with me and try your best to answer some questions. If you do not know what to say or do next, you can guess or say ‘I do not know’. It will take you about 20 minutes to do these things.

Are there good things and bad things about the study?

What we find in this study will be used to improve the living conditions for people living with dementia. As far as we know, being in this study will not hurt or agitate you.

Will you have to answer all questions?

No. If we ask you questions that you do not want to answer, then tell us you do not want to answer those questions.

Who will know that you are in the study?

The things you say and any information we write about you will not have your name with it, so no one will know they are your answers or the things that you did.

The researchers will not let anyone other than themselves see your answers or any other information about you.
Do you have to be in the study?

You do not have to be in the study. Just tell me if you don’t want to be in the study. And remember, if you decide to be in the study but later you change your mind, then you can tell us you do not want to be in the study anymore.

Do you have any questions?

You can ask questions at any time. You can ask now or you can ask later. You can talk to me or you can talk to someone else at any time during the study.

Kyle Plumb (Department of Geography and Planning)
(613-449-2140)
4kbp@queensu.ca

IF YOU WANT TO BE IN THE STUDY, SIGN YOUR NAME ON THE LINE BELOW:

Resident’s name, printed: ______________________________________________

Date: _____________________________

Signature of the Researcher: ____________________________________________

Date: _____________________________
Appendix IV Interview Guides for Family, Staff and Residents

Family

- Before we begin the interview itself, I’d like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at any time. This interview will take approximately 30 minutes.

- Do you have questions before we proceed?

What is your understanding of the philosophy/approach to care in the facility? Is it important that facilities include a rigorous philosophical approach?

How does this play out in your daily experience of the facility? Your loved one?

Do you think that the staff is educated and trained in a way that supports this approach?

Do you feel included in the decision-making process? Are you a part of the care team?

Can you comment on the role of the physical environment in the implementation of this approach? Social?

If you lived here as a resident/staff member what would you want changed? Given unlimited resources.

Anything that they feel I have missed or haven't had the chance to say regarding their experience?

Staff

- Before we begin the interview itself, I’d like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at any time. This interview will take approximately 45 minutes.

- Do you have questions before we proceed?

Specific role in facility? How long?

Your understanding of the philosophy/approach

Main goal

How does the philosophy support needs of residents, staff, family?

How does it play out in your specific everyday role?

How is it reflected in physical/social environment?

- "the knack"
  - what are the personal qualities/traits in staff/volunteers that they feel best support this approach? Can this be achieved through training or is it innate? Discuss.

- What role(s), if any do they feel that the physical environment plays in this approach?
- If not for this particular approach what would be different? Is this a meaningful difference?

- What are the challenges in implementing this approach?

- If you were a resident in this facility what would you like to have changed?

Anything that they feel I have missed or haven't had the chance to say regarding their experience?

**Residents**

- Before we begin the interview itself, I’d like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at any time. This interview will take approximately 30 minutes.

Questions before we start?

1.) Background Information
- What kind of things did you enjoy to do before you came here?

- How long have you lived here? (present)

2.) Experience of Facility
- What do you like about living here?

- What do you dislike about living here?

- What are your favorite things to do here?

- What is your favorite place/area to be in the facility? Why? What do you do there?

- What is your least favorite area to be in? Why? How do you feel when you're in this place?

3.) Social Relationships
- Do you have friends here? Who? (staff, other residents..)
- Who do you spend time with? (Why? What is that like?)

4.) Conclusion
- Is there something important I forgot? Is there anything else you think I need to know about your life here?
CALL FOR STUDY PARTICIPANTS

ARE YOU A STAFF MEMBER, RESIDENT OR FAMILY MEMBER OF A RESIDENT AT THIS FACILITY?

IF SO:

You are invited to participate in an important study conducted through Queen’s University exploring your daily experience in the facility especially as it relates to the Gentle Care approach.

What do I have to do?
Your participation will involve a one-to-one interview with the researcher, Kyle Plumb, consisting of 5-10 simple questions that facilitate a conversation about your daily experience(s).

How long will it take?
Each interview may last from 10-30 minutes depending on how much you care to share.

What if I refuse or change my mind?
Involvement in the study is voluntary and all necessary steps will be taken to safeguard the confidentiality of your personal information. You may withdraw at any time with no consequences to you or anyone else.

Who do I contact?
If you are interested in participating and/or would like to learn more about the study, please contact PhD Researcher Kyle Plumb at kyle.plumb@gmail.com; (613) 449-2140 or Director of Care ____ at _____

This study has been reviewed by and received ethics clearance through the General Research Ethics Board (GREB) at Queen’s University as well as the Fairmount Home Administration.