

A Case Study Exploring the Implementation and Lived Experience of Person-Centred
Dementia Care at The Lodge at Broadmead

by

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BAH, Queen's University, 2010

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Abstract

Older adults living with dementia are marginalized in society through the socially constructed binaries of old/young, able/disabled and ultimately us/them. These are manifested in a culture dominated by approaches towards illnesses that favor clinically inclined models of care which entail the search for cures rather than attention to the care required by and for individuals. To heighten their vulnerability, from an individual perspective, the cognitive nature of dementia often prevents people living with it from having a voice in their representation.

Person-centered care is a philosophy that recognizes the importance of who the individual is and where they are situated in an effort to create a more holistic care experience. The Lodge at Broadmead is a residential care facility that has operationalized an explicitly person-centered philosophy of care. The main objectives of this project were to gain an understanding of the lived experience and implementation of person-centered dementia care from the many different perspectives contained within this facility as well as the methodological barriers associated with including people living with dementia in this type of research. To this end, one-on-one interviews and focus groups were conducted with a total of 16 staff members and leadership at The Lodge at Broadmead as well as one resident. These were informed by a 4 month period of observation in the form of volunteer work.

Three main themes emerged around the implementation of person-centred care at The Lodge at Broadmead: identity maintenance, facilitating relationships, and aligning values. These themes represent the most important theoretical links between the physical and social aspects of the environment, and person-centred care's ultimate goal of maintenance and enhancement of personhood for the residents. Drawing from my own research experience, there were several methodological challenges in undertaking the research as well which were: the institutional necessity of consent by proxy, a rigid interview approach, and not enough time spent with the residents.

Keywords: dementia care, geographical gerontology, person-centred care, methodology

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Dedication

This paper is dedicated to my family who provide me with a platform to leap off, and a soft landing.

Chapter 1. Introduction

Health Geographers are interested in the complex transactions between people, place, and health, recognizing that the places we occupy reflect and affect who we are, how we are, and how we are perceived (Kearns and Moon, 2002). There has been a recasting of the key concepts of place and health from universal and static entities, to socially constructed, situationally dependent and dynamic ones. As a result, human geographers ground their work in the subjective, 'lived experience' of a place and explore how that experience affects the construction of identity and creates meaning for people (e.g., Ley, 1979 and Tuan, 1991). Similarly, the conceptual framework for understanding the nature of dementia and subsequently the role of dementia care has undergone a shift from a purely biomedical orientation with a curative bent, to a more holistic orientation emphasizing social and psychological aspects of care while acknowledging neurological degeneration. This 'culture shift' from cure to care, often characterized by an adherence to the philosophy of 'person-centred care', is highly cited in literature and acknowledged by many institutional facilities caring for vulnerable older adults. However, this view/approach/orientation may not be as visible in the day to day reality of actual dementia care practice. Marrying these two conceptual shifts, the purpose of this project is to apply a geographical theoretical and methodological framework to explore the lived experience of individuals in a residential care environment that is informed by an explicitly 'person-centred' philosophy of care.

1.1 Research Context: the intersection of three disciplines

Previously referred to as ‘medical geography,’ **health geography** has also undergone a fundamental conceptual shift in the past decade. Underlying the semantic change is a re-engagement with the core concepts of place and health to present a more complex and nuanced version of the physical and social world and people’s experience of it (Johnston et al., 2000; Kearns and Moon, 2002; Rosenberg, 1998). Kearns and Moon (2002) note that, “The shift [is] indicative of a distancing from concerns with disease and the interests of the medical world, in favour of an increased interest in well-being and broader social models of health and health care” (p. 606). Moon (2009) identifies four necessary contexts that helped shape the semantic shift. First, the biomedical model of health began to lose its dominant epistemological position as geographers began interacting with post-structural social theorists such as Foucault and Illich. Second, the disease ecology paradigm that had established dominance in medical geography in the 1970s had lost its appeal for some human geographers who began to view it as overly deterministic and therefore of limited explanatory value. Third, stemming from the interest in health inequalities and structural social theories, human geographers began to look at determinants of health outside of disease and death, such as socio-economic status. This led to a focus on how behaviors that influence health are affected by structural factors. Last, the loss of trust in the biomedical version of health led to an increasing concern in geography with non-medical aspects of care provision such as health policy and its spatial representations. The core concepts of health, place, and the body as they relate to aging and dementia care are further examined in chapter two.

The cultural and spatial turns that took place within human and health geography have had major implications for the subdiscipline of **geographical gerontology**. Centrally, the re-imagining of place as a ‘living construct’ and its power to invoke situated experiences of health and well-being has repositioned enquiry into its role in the construction and experiences of aging. As well, other disciplines in the social sciences such as sociology, anthropology, and psychology have become more interested in the construction and quality of places resulting in an interdisciplinary approach to the study of aging in place (Andrews and Kearns, 2005). Andrews et al. reflect on the status of this discipline in their (2007) paper, *Geographical Gerontology: The Constitution of a Discipline*: “Mirroring theoretical developments and diversity in the social sciences, the future research challenges that lie ahead will involve the articulation of varied and often hidden cultural practices and social processes, and hitherto taken-for-granted—as well as new—social and spatial relations, between older people, health and place” (p. 151). This research project addresses the challenge posed by Andrews and others by employing a theoretical perspective that spans across three disciplines as well as a qualitative and interpretive methodological approach to the subject matter.

Aligned with shifts in the conceptions of aging, health, and place is a cultural shift in the field of dementia care that represents a change in the way we view dementia, the role of the caregiver, the behaviour and status of people living with dementia, and the emphasis/approach for research. This shift has its roots based largely in the philosophy of person-centred care.

Similar to the conceptions of health and aging in health geography and geographical gerontology, **person-centred** care frames dementia as a simultaneously

social, physical and psychological notion. The primary goal of dementia care is viewed as maintaining and enhancing personhood while accepting neurological realities. Tom Kitwood (1997) defines personhood as, “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (p. 8). This status or standing as a person requires trust, recognition and respect. Person-centered care espouses these values as well as values such as dignity and choice in the caregiving context, where the adherence to these values results in the acknowledgement of the person with dementia as a unique individual, further validates their emotional reality, and supports their lived experience (Kitwood, 1997). Moreover, a person-centred approach to care advocates for the value of all people as individuals regardless of age and health status, emphasizing the perspective of the person with dementia (Brooker, 2004). Methodologically, a person-centered approach would involve doing research ‘with’ rather than, ‘for’ or ‘on’ people living with dementia in an effort to give this vulnerable group a voice in their own representation.

1.3 Research Goal

The overall goal of this research project is to explore how a person-centered philosophy of dementia care is put into practice in a residential care facility and to consider how it then affects how the individual experiences their environment. Three specific research objectives guide this explorative, qualitative project.

1.4 Research Objectives

1. **Theoretical:** This project explores the implementation and lived experience of person-centred dementia care in a residential care facility through a broad lens drawing upon concepts from the fields of human/health geography, geographical gerontology, and dementia care. In doing so, it has potential to offer new, more holistic and nuanced, perspectives and understandings of the concept of person-centred care and its implementation.
2. **Empirical:** A qualitative, thematic analysis of in-depth interviews with leadership, staff, and residents in a residential care facility is conducted in order to 1) consider the roles of the layers of the environment (physical, social, psychological) in implementing the philosophy of person-centered care 2) represent the perspective of the resident's in their experience of this person-centred environment and 3) address and discuss the methodological barriers encountered to inform further research.
3. **Knowledge translation:** The information gained may be employed to contribute to the culture shift in care; representing a facility that is at the forefront of the movement. As well, presenting the findings back to the facility can help to inform future developments in the care environment in which the study is set. Though not intended to be generalizable given the small scale of this study, some of the insights from these findings may be used to inform community care policy and assist decision-makers in residential care more broadly to create environments which contribute to the maintenance and enhancement of personhood for older residents with dementia.

1.5 Structure of Thesis

This introductory chapter has set out the aims and context of the research. The next chapter will review the relevant literature, elaborating on the research context and situating this project within the broader disciplines of health geography and geographical gerontology. The third chapter details the methodology for the study, outlining the qualitative design and research procedures used to meet the research objectives. Chapter four conveys the study's findings which are based on the frameworks described in the literature review. Chapter five is a discussion of the methodological barriers and lessons learned throughout the project. Finally, the concluding chapter reiterates the key findings, places them in the context of the existing literature and concludes with some study limitations and future directions.

Chapter 2 Literature Review

The goal of this chapter is to explore the literature related to health geography, aging, and dementia care in order to situate this project at a conceptual intersection between these fields. This chapter answers the question: how can human geography contribute to the fields of health and aging and more specifically to dementia-care? In other words, it explains why place matters with respect to health, especially for vulnerable older populations such as people with dementia living in residential care. Conceptual and methodological shifts in the fields of health geography and geographical gerontology are reflected on in order to bring the similarly positioned shift in the culture of care for people with dementia to light. This chronological portrayal also serves to emphasize that these fields are dynamic and constantly evolving through interactions with broader philosophical thought about how the world is, and how we can study it.

The chapter begins with an introduction to the cultural and spatial ‘turns’ that have blurred the conceptual boundaries between human geography and other social sciences. These paradigm shifts in the social sciences have changed the way geographers think about space and place, corresponding to the critical interest in other disciplines with some of these concepts. For example, the resulting shift from ‘medical’ to ‘health’ geography and the consideration of ‘aging in place’ in geographical gerontology are considered in order to frame this project within the breadth of these two sub-disciplines. The culture shift in dementia-care that is viewed as being aligned with the previously discussed conceptual shifts is then outlined to situate the philosophy of person-centred dementia care alongside contemporary geographical and gerontological frameworks.

Finally, the rationale and implementation of a person-centred methodological approach is considered along with the difficulties associated with doing research with people living with dementia.

2.2.1.2 Cultural Turn in Human Geography

Jackson (2010) describes the cultural turn as “an intellectual recognition, within human geography and the wider human sciences, that all claims about the world and knowledge are mediated by culture” (p. 645). The implication is that representations of people, places and things, do not merely reproduce or explain what they assert. Instead, it is the representation that fundamentally constructs objects of the world through cultural practices such as language, history, politics, identity, and interpretation (Jackson, 2010). Jackson (2010) tells us that underlying arguments from the cultural turn are the beliefs that “knowledge produces the world, rather than simply mirrors it” (p. 645), and knowledge claims are, “complex products of particular contexts and specific perspectives and are shaped by forces such as history, gender, class, race, and location” (p. 645). Importantly, these foundational beliefs preclude the possibility of objective knowledge as any claim to objectivity would ignore its culturally contingent and situated nature. In this ‘new’ cultural geography, culture is envisioned as a process through which people make sense of the world (Du Gay and Hall, 1996). It is therefore seen as a fundamental process in shaping societies and creating nuanced and intricate human landscapes. Marcus (2000) states that “what the cultural turn has meant for geography is a strong infusion of interpretative theories, methods and ideas in a field heavily influenced by tasks of

mapping, describing societies spatially” (p. 14). The theoretical framework of the cultural turn is, in large part, derived from an interaction with postmodern philosophies.

Ontologically, postmodernism has two main thrusts. First, the rejection of any ‘metanarratives,’ or ‘grand theories’ that position the world as being fundamentally conditioned or ordered according to a central logic. Instead, the world is viewed as being made up of many different and equally valid perspectives (Phillips, 2010). This comes from the growing general recognition that some elements of the physical and social world do not fit within any overarching structure or logic and entails more localized ontologies “whereby events, phenomena, and processes emerge because of the particular relationships that come to exist between all manner of elements that are co-present within particular times and spaces” (Phillips, 2010, p. 2267). This skepticism of grand theories is echoed in Michael Dear’s (2000) statement that postmodernism is a philosophical framework, “free from the search for ultimate foundations for everything” (p. 35).

Second, postmodern ontologies include a concern with difference and the problematization of modernist, binary categories of difference (Phillips, 2010). This arose from a critique of the modernist assumption that explanation is properly found by establishing similarities between events, objects, and processes. Explanations based on this assumption are seen as illusions since they tend to be based on essentialist beliefs about categories created by false dichotomies such as rural/urban, male/female, able/disabled, diseased/non-diseased where individuals must be one or the other (Phillips, 2010). These relationships are seen as being much more diverse and nuanced than proposed by modernist theories. Moreover, focusing on similarities tends to ignore

people who don't fit, in one way or another, with the social norms of a group, i.e., the so-called outliers.

Epistemologically, postmodernism represents a critique of the correspondence theory of truth/representation, as well as stressing the situatedness of knowledge (Phillips, 2010). The former is aligned with a post-structural critique of the correspondence theory of truth based on the idea that concepts expressed through language do not necessarily mimic/correspond to anything beyond symbols or other concepts. There is no underlying or absolute truth to a statement that exists outside of the interpretation of language (Phillips, 2010). Thus, the language or text itself becomes the source of knowledge and consequently, the object of inquiry. The latter idea of situated knowledge is in direct contrast to the objective epistemological stance of many modernist theories where the ideal researcher is a detached, disembodied viewer of the world. Contrary to this view, post-modern epistemologies assert that knowledge is always constructed from a certain position or perspective. Consequently, localized and contextualized epistemologies are created which reflect upon the situationality and positionality of the knower and how this context influences the knowledge outcome (Phillips, 2010).

2.2.1.3 Spatial Turn

Along with the cultural turn in geography, the spatial turn represents a bridge between the theories and subject matter of geography and other social sciences. The spatial turn is an appreciation across the social sciences and humanities that “Geography matters, not for the simplistic and overly used reason that everything happens in space

but because *where* things happen is critical to knowing *how and why* they happen" (Warf, 2010, p. 2669). This appreciation for space and place in other disciplines has led to a multidisciplinary approach to the understanding of the human experience that is more contextualized and nuanced than previously thought of in geography (Warf, 2010). Furthermore, Denis Cosgrove (1999) argues that the spatial turn "corresponds to post-structuralist agnosticism about both naturalistic and universal explanations and about single-voiced historical narratives, and to the concomitant recognition that position and context, are centrally and inescapably, implicated in all constructions of knowledge" (p. 2). Here we can see a strong philosophical relationship between the cultural and spatial turns. This implies that they had parallel theoretical influences on geography and other social sciences. Barney Warf (2010) tells us that "The spatial turn reflects broader transformations in the economy, politics, and culture of the contemporary world" (p. 2671). Therefore, visions of geography can only be understood with respect to its social and spatial contexts and Warf pinpoints three main forces that have acted together to elevate and problematize the concept of space: Globalization, the rise of the Internet, and increasing attention paid to worldwide ecological and environmental issues. These, coupled with the cultural turn in geography, reinvigorated the discipline into a dynamic social science whose ideas about space were influential enough to be borrowed by other social sciences thus blurring the boundaries between disciplines (Hubbard et al., 2002).

The spatial and cultural turns have had a profound effect on human geography. These impulses are manifest in a contemporary post-modern approach to human geography that "encourages analysis of socio-spatial relations within a specific context without claims for universality or scientific rigour" (Hubbard et al., 2002). Coupled with

this situational knowledge is sensitivity to differences between people. This sensitivity brings about inquiries into how people are defined as being different from the norm and how this is constructed in specific places at specific times (Phillips, 2010). By providing socio-spatial accounts that are sensitive to the views of those on the margins of society, post-modern geographers challenge dominant and universalistic claims to knowledge. Another manifestation/reaction to the cultural and spatial turns involves geographers taking a more critical approach to the relationship between people and space.

2.2.1.5 Critical Human Geography

Although not representing a specific philosophical approach, critical geography is an important movement in terms of its goals which tend to address issues of social justice. For Hubbard et al (2002), critical geographers, though not necessarily philosophically cohesive “are united in general terms by their ideological stance and their desire to engender a more just world” (p. 62). Echoing the postmodern concern for difference, critical geography emphasizes the voices of marginalized groups in order to problematize and deconstruct the social construction of binary categories such as able/disabled, old/young, us/them. As a result, critical geographers are concerned with employing methodologies that allow them to incorporate the voices of marginalized and silenced groups. This is coupled with reflexivity from critical geographers who are aware of their positionality and the situatedness of knowledge produced (Harvey, 1996). The key theme in critical geography is a question of how inequality is “always played out in, and through, the many spaces of the world” (Sharp et al., 2003 p.1). Social inequalities are viewed as being spatially structured and space is viewed as a political construct.

This research project may be seen as contributing in the areas of postmodern and critical movements in human geography as its focus is on representing the views and experiences of a vulnerable group and thereby providing a discursive space within which their voices can gain greater attention and consideration in their own representation.

Qualitative methods are used to explore the subjective and situated interpretations of the person/place/health relation. This project may also be seen as contributing to the spatial and cultural turns as it exists at an intersection of the fields of health geography, geographical gerontology, and dementia care in an effort to offer an interdisciplinary perspective on the experience of living and working in a residential care facility.

The rest of this section will describe the concepts of place, body and health/disease as they are currently thought of in health geography and how they link to geographies of aging.

2.3.1 Health and aging

As noted, the traditional view in medical geography conceptualizes health within a strictly biomedical framework as the lack of disease (medically defined ailments). This approach is reductionist rather than holistic and views death and disease solely in terms of singular disturbances to internal pathology of the human body with no regard for social determinants or contexts (Moon, 2009). As a result, to properly understand and address biomedical health you must engage with scientific disciplines such as chemistry and biology as they are applied to the human body, as well as undergo training in physiology, pharmacology, surgery, and other interventions that are employed to reverse the disease process. This understanding of health emphasizes physicians, for example, as the solitary

voice of the biomedical model and hospitals as the key sites of care. Through the influence of social theorists like Foucault and Illich, the concept of health in geography has moved from being cast in its most negative (i.e., illness vs wellness) and narrow sense of not being physically or mentally ill to a broader positive sense of physical, emotional and social well-being (Curtis, 2004). Foucault's (1975) concept of the 'Medical Gaze' and Illich's (1976) 'Iatrogenesis,' cast doubt on the benefits of the hegemony of the biomedical model of health. This doubt was influential in health geography for the emergence of a more social model of health that began to be represented as a socially produced, rather than a fixed biological construct. Further, the socio-ecological model of health focuses on the context in which an incidence of disease is located; beyond the immediacy of the diseased body to the more holistic and fundamental social causes (Moon, 2009).

Health geographers have advocated for this more enlarged and positive view of health in accordance with social models of care that support policy oriented towards ideas of empowerment and well-being as opposed to the view of health as a "state of absences" (Kearns and Collins, 2010). This redirects the discussion about health care from an emphasis on curing diseases in acute care hospitals, to acknowledging the social and psychological aspects of health care that are inextricably linked to the physical, social and psychological contexts of the places that it occurs (Curtis, 2010). As well, the adoption of the social model of health shows that health geographers are concerned with aspects of health and well-being that are outside the medical domain (Curtis, 2010).

The broadening of the definition of health to include social and psychological factors implies that a diseased body does not preclude the health and well-being of the

inflicted person. This is especially important for people with long-term/chronic illness such as dementia; they may not ever be rid of the physical illness. Thus, acknowledging and enhancing the social and psychological aspects of health is crucial. The philosophy of person-centred care is closely aligned with this holistic interpretation of health as it has roots in the idea that when biological health may be wavering, the focus should be on social and psychological aspects. Moreover, this is especially important for older adults as the prevalence of dementia increases with age (Alzheimer's Society of Canada, 2009).

Issues concerning the perception and treatment of older adults are magnified due the rapid aging of a large percentage of Canada's population, a trend which will likely continue for several decades (Hodge, 2008). This shift is not solely a demographic one however, it is also coupled with social and political changes that are required to support and care for greater numbers of older adults and their caregivers. In order for the social and political changes to align with the specific needs of this group there must first be a deeper understanding of people within the group. Instead of assuming homogeneity of identity throughout the cohort of older people in Canada, we must recognize individual complexity and heterogeneity within this group to come up with any meaningful solutions. This individuality is explained by Bond et al (1993) who note "the courses of development of different people are likely to diverge the longer they live, and the more experiences they absorb. Rather than growing more alike as we age, we therefore become more individual" (p. 30).

Similar to the concept of health, aging has been reimaged as a social process as much as it is a biological/chronological one. As McHugh (2003) notes "Ageing is not only an embodied process but is emplaced as well" (p. 160). The social aspect of aging is

characterized by cultural and individual expectations of how people should act as they get older. Ageism, a term used to describe the negative stereotypes associated with older people, old age and the aging process, is prevalent in western society (Bytheway, 1995; Chappell, et al., 2007). Physical changes that accompany aging are ascribed negative social meanings in a process based on our cultural obsession with youth. In this sense, we age socially because of the attitudes towards our physical aging. Underlying this process is the plotting of old and young as binaries in direct contrast to one another. The outcome is that older people are often seen as unproductive and incompetent, where younger people are celebrated as beautiful and vital (Bytheway, 1995). Additionally, older people and the aging process may represent unconscious anxieties based on inevitable physical decline, dependence and eventually death (Kitwood, 1997). This leads to a type of social exclusion as people may not want to face their own mortality, and is manifest in social policy and quality of social services for older people (discussed further in the next section).

Studies in health and aging are linked both practically and theoretically. Regarding the former, Janine Wiles, a prominent geographical gerontologist, tells us that “older people represent a significant proportion of the population with health conditions and as such a substantial proportion of the [geographical gerontology] literature is, and probably always will be, focused on their health and health and social care” (Wiles, 2005, p. 1). Theoretically, studies in health and aging are linked through the notion of ‘place’ as a ‘living construct’ that has emerged as a central organizing concept in health geography has been incorporated in research on older people (Andrews and Phillips, 2004).

2.3.2 Placing health and aging

Prominent health geographers Kearns and Moon (2002), state that “An awareness of place as a socially constructed and complex phenomenon has been a talismanic point of reference for the new health geography” (p. 610). This changing conceptualization of place is largely informed by health geographers’ engagement with postmodern and poststructural perspectives that arose through the ‘cultural turn’ in the social sciences. Moreover, Kearns and Joseph (1993) help explain exactly why places matter with respect to health by commenting that “without an understanding of place to enliven the otherwise abstract and geometric spatial landscape, our conclusions will be devoid of the human nuance and ambiguity that characterize the places in which we live out our lives” (716).

Research on ageing and its place has both anticipated and reflected the shifting perspective of place in health geography (Andrews and Phillips, 2004). Wiles (2005) provides us with the features of ‘place as process’ as it is conceptualized in geographical gerontology. These are listed in Table 1 along with an application of each feature in the context of the care of older adults. It is important to note that in reality these features of place overlap and interact simultaneously.

Table 2.1. How do geographical gerontologists conceptualize place?

Place Conceptualization	Context of the Care of Older People	Reference
Places are processes	Family/lay caregivers who live <i>with</i> an older person requiring care tend to provide more hours of assistance, and undertake a more diverse range of caregiving tasks, than those who live apart from care	(Keating <i>et al.</i> , 1999)

	recipients	
Places are subject to ongoing negotiation	The ways that we think about the appropriate location for care of older persons have changed over time. Demographic and socio-economic changes, including increasing proportions of older people in general populations, greater life expectancy, and improved health and independence amongst older people, have contributed to a growing emphasis on community-based care and care in homes	(Teeland, 1998)
The many different experiences and contested interpretations of places (some of these may compete or conflict)	In institutional settings, we can observe similar competing experiences and needs of place. For example, while paid care workers may have to juggle clinical demands in the context of being understaffed and overworked and hold a broad clinical knowledge, lay or family caregivers see the place as holding the potential to meet the needs and interests of their loved ones and have a deep knowledge of that particular person and their characteristics and well-being	(Raudonis & Kirschling, 1996)
Power relations are expressed through, and shape, places	Care is gendered and...The majority of those providing care to older people, both on a paid and unpaid basis, are women.	(Abel, 1991)
Places are interrelated – to other places, at different scales, at different times	Government policies about benefits for residential care might impact on other policy goals to promote older persons' independence by influencing decisions about institutional care vs. home support	(Clarkson <i>et al.</i> , 2005)
Places are simultaneously material/physical AND symbolic and social	The way that people symbolically understand a place, such as a hospital bed, will shape their social experiences of that place and	(Whittaker, 1995)

	their physical use (or not) of it. If a place such as a hospital bed is associated with ideas of fear or with negative past experiences, further experiences are likely to be tinged with those ideas and memories.	
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Adapted from Wiles (2005)

Building on the work of Lawton, Rowles, and Rubenstein, Peace et al. (2006) examine the relations between place, health and identity for older adults through a framework that involves a multi-layered environment with temporal aspects as well. In this framework, the place and space that a specific person or group occupies is thought of as an environment. Their understanding of themselves and their culture is affected by this environment which consists of multiple layers and can also be examined on various levels/scales, (Peace, et al, 2006; Oswald and Wahl, 2005). Environments can be examined on the micro-, meso- and macro- scales and separated into their physical, social, and psychological facets. The physical environment describes the material aspects of a specific space. The buildings and structures that are put in a space help to shape the behaviors and relationships of people within that place. The social aspect of the environment “reflects the ways in which people utilize their social capital to occupy, use, and organize their surroundings” (Peace, et al., 2006, p. 9). Relationships that exist between the people who share a physical place further shape how that place is experienced. The psychological environment reflects the subjective experiences and meanings attached to a place and space. An environment can then be understood as a layered physical, social, and psychological space within which our experiences take shape.

The environment can also be viewed as existing at different scales or levels namely micro, meso and macro (Peace, et al, 2006; Calkins, 2001). The environment at the macro level exists outside of individuals as well as their immediate surroundings. It can be seen as global, international, national, regional, or local in scope; beyond the internal and intimate world of the individual and his/her immediate surroundings. Some examples of macro-level environments are: socio-political ideology, globalization, cultural values and bio-medicalization of health care, all of which play a part in the personal experience of a place. The meso-level features of an environment are the components that immediately surround the individual (e.g., neighborhood, community). Patterns of social interaction within a facility as well as the physical arrangement within that space could be called meso-level attributes of the environment. Micro-level features of an environment are seen as immediate surroundings of the individual or group. Social interactions, sense of place, specific rules and policies and characteristics of a specific group or individual could all be placed in the category of micro-level environmental features. Although they can be separated theoretically, each individual simultaneously inhabits or is influenced by the micro, meso, and macro environments along with the physical, social and psychological environments, thus we can think of the environment of an older individual or group as being multiple and layered as well as temporal (Peace et al., 2006).

The idea that places matter with regard to health and identity has been taken up similarly in health geography through the conceptualization of *landscapes* lending an enriched awareness of “the cultural importance of place and...the development of place-specific landscapes of health care and health promotion” (Kearns and Moon, 2002, p.

610). Landscapes, contrary to the traditional, static conception, are now thought of as being assemblages of features, “influenced by physical and built environments, a product of the human mind and of material circumstances [reflecting] both human intentions and actions and the constraints and structures imposed by society” (Gesler, 1992, p. 743).

Gesler (1992) provides a link between health, aging and place in his concept of ‘therapeutic landscapes,’ which he describes as a “geographic metaphor for aiding in the understanding of how the healing process works itself out in places” (p. 743).

The theoretical notion of *therapeutic landscapes* has evolved alongside its core concepts of place and health (Williams, 1999; 2002; 2007; 2010). In general, therapeutic landscapes link ‘health’ and ‘place’ by analysing the ways in which certain places influence health status – potentially either in a positive or negative manner. Gesler’s (1992) model included two main categories within which he grouped characteristics of therapeutic places. The “inner/meanings,” theme contains characteristics such as the built environment, natural settings, sense of place, symbolic landscapes, and everyday activities while the “outer/societal context,” theme includes characteristics such as beliefs/philosophies, social relations/inequalities, and territoriality (Williams, 1999). This framework was applied to Gesler’s research on traditional sites of healing such as the Asclepian Sanctuary at Epidauros, Greece and Roman Baths at Bath, England and provided the basic model from which subsequent applications were projected. Building on Gesler’s ideas while taking into account the socio-ecological perspective of health, Williams (1998) broadens the definition of therapeutic landscapes to refer to: “those changing places, settings, situations, locales, and milieus that encompass both the physical and psychological environments associated with treatment or healing; they are

reputed to have an enduring reputation for achieving physical, mental, and spiritual healing” (p. 1193). Applications of the therapeutic landscapes concept have used it as a framework to take into account the physical, social and psychological aspects of the landscape/environment in order to acquire a more holistic interpretation of outcomes for people (e.g., Cutchin, 2007; McLean, 2007).

Both of these frameworks (therapeutic landscapes and the multi-layered environment) are helpful for this research as they provide a blueprint for the analysis in chapter 4. At that point The Lodge At Broadmead’s implementation of person-centred care is arranged into its social and physical domains in an effort to gather a greater understanding of the environmental and the person-centred philosophy as a whole.

2.3.3 The Body

Parr (2002) and Dyck and Moss (1999) introduce us to the term ‘sociobiological’ to describe the body as it is envisioned from a health geography perspective. This view takes into account “the ways in which bodies are both socially constructed and materially experienced” (p. 243). The biological aspect of disease is acknowledged while at the same time a sociobiological perspective recognizes how disease is constructed through medical science and cultural attitudes (Parr, 2002). Ill bodies are not understood as diseased objects, but rather as being created and recreated through a “complex signification process whereby the ill body becomes socially, economically and politically legitimatized, combined with a nuanced appreciation of how the material body is experienced through such inscriptions” (Parr, 2000, p. 244). Similarly, Dorn and Laws (1994) note that it is important to register the human body as more than just “a host to

some lesion or pathology waiting to be ‘discovered’ by the medical practitioner, and thus to recognize the variability of the human person?, complete with differing material circumstances and cultural ascriptions bound up with its particular place in socio-spatial hierarchy” (p. 107)

2.3.4 Disease/ Embodied Geographies of Disease

If health is more than just the absence of disease, how, then, do health geographers understand disease and its relationships with health and the body? In contrast to the biomedical view of diseases as strictly biological disturbances, Del Casino Jr., in his (2010) contribution to *A Companion to Health and Medical Geography*, suggests that, “diseases are more than biological processes operating in and across space; they are social processes that have real effects and affects for individuals and communities” (p. 188). Diseases, then, are not static objects. Their impact is felt differentially through time and space based on the individual and society-wide contexts in which they exist. As a result of this multi-faceted view of disease, geographers are interested in how the experience of various diseases is played out in places and spaces including our bodies.

In contemporary health geography the body is not viewed as simply an object in space. Rather, the body is a space that is constituted materially and socially through its relationship with other bodies and spaces (Del Casino Jr, 2010). Similarly, Del Casino Jr (2010) tells us that the diseased body is more than a physical artifact that has contracted a virus or encountered a genetic change, “it is also a social body marked by the socio-cultural and political-economic meanings societies ascribed to the ‘productive’ citizen or the ‘normal’ person” (p. 190-191) and laying well beyond an exclusive focus on the

health care realm. The experience of a disease is thus a subjective concept that can be studied only through an interpretive framework rather than a scientific one. Since the experience of a disease is contingent upon where, when, and how the diseased person conceptualizes their relationship to the condition, tracing the embodied experience of living with a disease demands that we understand disease as a fluid process that changes over time and place (Del Casino Jr, 2010). To this end, many geographers have been interested in qualitative methodologies that investigate the complex nature of living with various diseases from subjective to more objective positions (i.e., Moss and Dyck, 2002; Meade and Erickson, 2000; Phinney and Chesla, 2003). From this position, this thesis moves to a consideration of the specific illness or disease of dementia. This is where a tie to PCC will be made later so perhaps you should say something here to build the connection later.

1.2 Dementia: Physical and Social-Psychological Effects

McKhann et al. (1984) provide us with a widely accepted definition of dementia produced by neuroscientists and doctors in the USA:

Dementia is the decline in memory and other cognitive functions in comparison with the patient's previous level of function as determined by a history of decline in performance and by abnormalities noted from clinical examination and neuropsychological tests. A diagnosis of dementia cannot be made when consciousness is impaired or when other clinical abnormalities prevent adequate evaluation of mental state. Dementia is a diagnosis based on behaviour and cannot be determined by brain scan, EEG or other laboratory instruments, although specific causes of dementia may be identified by these means (McKhann et al., 1984, p. 21)

From this definition we can see that dementia relates to the person and their behavior as a whole, not just the brain. It is indicated by a decline in cognitive performance from previous levels and, as a general rule, is likely to arise if a person shows a decline in memory and at least one other cognitive function (Kitwood, 1997). Moreover, it is a speculative rather than a definitive diagnosis. Once a diagnosis of dementia is reached further analysis of physiological and pathological processes is required to place the particular case as that of a primary or secondary dementia. Primary dementias are those which are obviously linked with damage to brain tissue; secondary dementias are those associated with other pathologies or physiological disturbances (Kitwood, 1997).

The three main categories of neurologically degenerative processes associated with dementia are Alzheimer type, vascular type, and mixed – a combination of the former two (Kitwood, 1997). Alzheimer type pathology is characterized by a general loss of neurons, overall atrophy, and degeneration of cell structures in the brain. Vascular pathology refers to any case where dementia is associated with a lowered supply of blood to the brain. Dementia is categorized as *mild* if a person has the ability to live independently; *moderate* if some assistance is required for tasks of daily living; and *severe* if persistent help and support are required (Kitwood, 1997).

A person with dementia experiences two main types of changes. The first is neurological and is typically associated with a degeneration of the brain structure leading to a decline in brain functioning and efficiency. Behaviourally, this leads to the gradual failure of mental capabilities such as memory, reasoning, and comprehension (Kitwood, 1997). Second are changes in the social-psychological environment. These can typically

be found in dysfunctional or malignant social interactions that occur based on incorrect assumptions about the afflicted person (Kitwood, 1997; Sabat, 2001; McLean, 2007). It is impossible to distinguish between the outcomes of neurological and social-psychological (personal) changes but there is no doubt that they both play a role in the dementing process. Moreover, each individual experiences the disease uniquely based on their unique experiences throughout the life course (Kitwood, 1997).

If the care needs of an individual with dementia cannot be met in their home, they may be required to relocate to a facility that can provide this care. As the incidence of dementia increases along with the aging of the population, it becomes paramount that these facilities are able to properly account for the complex care needs presented by individuals in this group.

1.2.5 Residential Care

Often referred to as complex care, nursing homes, long-term care or extended care, residential care is provided for people who require 24-hour supervision, personal nursing care and/or treatment by skilled nursing staff and takes place in a community care facility. This is not to be confused with assisted living facilities whose services include housing, hospitality and personal care services for people who are no longer able to live at home independently, but who do not need 24-hour nursing care. Emphasizing the changing face of residents entering these facilities, the Canadian Study on Health and Aging conducted by Graham et al. (1997) suggests that 50% of older adults within residential care have a diagnosis of dementia with an additional 30% having the diagnosis of Cognitive Impairment. Moreover, since beds are reserved for those who require 24

hour care, those with dementia are likely experiencing moderate to severe symptoms. As a result, it is imperative that these facilities foster a culture of care that can meet the complex care needs of this vulnerable population.

In their (2012) report, Changing the Culture of Care, Purveen and Drance provide us with a guideline that outlines the general care needs of people with moderate to severe dementia symptoms:

1. To be known first as a person with a rich and complex story that is understood and valued.
2. To be recognized as a member of a family. The family members also have important needs for education and support, which if properly addressed, will improve their relationship with their family member with dementia, and improve their ability to be collaborative partners in care with the interdisciplinary team.
3. To have an accurate diagnosis, where the prognostic trajectory is acknowledged and respected, and communicated with family members.
4. To have medical excess disability minimized through the timely recognition and treatment of acute illnesses that emerge, the optimization of chronic illness care with excellent symptom management and sensory functioning, support to enhance mobility, and the appropriate use and review of medications, while avoiding poly-pharmacy when possible.
5. To have direct care providers who are educated in personhood and are committed to enhancing dementia care through their attitudes, knowledge and skills. The care providers need to be coached and supported to provide optimal dementia care. A sufficient number of care providers must be available to provide holistic personhood-honouring care. Most effective is consistency of care, with ongoing assignments to neighbourhoods rather than moving between units and people with dementia without the possibility of building relationship. Care providers need to be supported to be creative in their care giving and viewed as valued members of the interdisciplinary team.
6. To live in a physical environment that is homey, small enough for effective navigation, which supports maintaining mobility, yet large enough to have space between people so as to minimize

negative interpersonal conflict. The physical environment must allow access to valuable useful outdoor space, have bathrooms that look and feel like home, and use space to optimize social interaction and visual cues to enhance the person's capability.

7. To live in a facility with a culture and philosophy of care that balances care for the human spirit and the human body and is dedicated to building a community both inside and outside the facility. (p. 7)

Although much research has been done regarding the quality of life and well-being of people with dementia residing in residential care, it is still recognized as a key area where improvements are both needed and possible (Vladeck, 2003; Purveen and Drance, 2012). Indeed, while research describes many optimal care practices and physical environments, the translation of that knowledge into everyday practice is not a full reality in many residential care environments (Albinsson and Strang, 2002). Instead, these environments tend to be over-medicalized settings oriented towards efficiency in completing care tasks and away from quality of care following an institutional model of care that was created for acute care hospitals. Literature suggests that a culture shift in long-term care that includes a society-wide shift in how we understand dementia, founded upon a person-centred philosophy of care, is required to meet the needs of this growing population (Kitwood, 1997; Purveen and Drance 2012; Vladeck, 2003).

2.5 Culture Shift in Dementia Care

It is increasingly understood that substantial change must occur to replace the current institutional or biomedical model of care with an alternate, more holistic and inclusive model of care (Kitwood, 1997; Sabat, 2001; Puurveen and Drance, 2012). This is often referred to as a need for "culture change." In geography, culture is a contested term often thought of as, "a shared set of meanings, that are lived through material and

symbolic practices of everyday lives,” (Knox et al., date?) or as, “specialized behavioural patterns, understandings, adaptations and social systems that summarize a group of people’s learned way of life” (Fellman et al., 2005). In the context of dementia care, Kitwood (1997) describes culture similarly as, “a settled, patterned way for providing meaning for human existence, and for giving structure to action within it” (p. 134). He outlines three aspects of culture that are salient for the analysis of dementia care. First, institutions/organizations act to embody vested interests and produce knowledge that justifies those interests. Second, norms, which create a standard for acceptable behavior, become internalized. Third, beliefs/assumptions about what is real and true become taken up as common sense. As a result, to change a culture involves challenging not only privilege and power, but also the dismantling of an engrained world-view (Kitwood, 1997).

According to Kitwood (1997), Sabat (2001) and many others, throughout the process of dementia a self remains and thus the goal should be both to recognize that self and enhance the continuing abilities of the afflicted person. This ‘personhood maintenance’ requires a shift from the ‘old,’ biomedically-oriented culture of dementia care, to the ‘new,’ person-centred culture. This is where a link from above can be made back to geography and embodiment.

2.5.1 The old culture and the new

This section describes the nature of the culture shift in dementia care in more detail as well as providing some examples of specific approaches to care that have emerged from the new culture. In doing so, TLAB’s model/approach to dementia care is

situated within the culture shift in general as well as more practically as a hybrid of these specific approaches. The following excerpt is from Kitwood (1997), who, after spending some time in a dementia care setting that epitomized the old culture of care, attempted to represent the experience of living there:

You are in a swirling fog, and in half-darkness. You are wandering around in a place that seems vaguely familiar. And yet you do not know where you are; you cannot make out whether it is summer or winter, day or night. At times the fog clears a little, and you can see a few objects really clearly. But as soon as you start to get your bearings, you are overpowered by a kind of dullness and stupidity. Your knowledge slips away, and again you are utterly confused.

While you are stumbling in the fog, you have an impression of people rushing past you, chattering like baboons. They seem to be so energetic and purposeful, but their business is incomprehensible.

Occasionally you pick up fragments of conversation, and have the impression that they are talking about you. Sometimes you catch sight of a familiar face. But as you move towards the face it vanishes, turns into a demon. You feel desperately lost, alone, bewildered, frightened.

In this dreadful state you find that you cannot control your bladder, or your bowels. You are completely losing your grip; you feel dirty, guilty, and ashamed. It's so unlike how you used to be, that you don't even know yourself. And then there are the interrogations.

Official people ask you to perform strange tasks which you cannot fully understand: such as counting backwards from one hundred, or obeying the instruction: 'If you are over 50, put your hands above your head'. You are never told the purpose or the results of these interrogations. You'd be willing to help, eager to co-operate, if only you knew what it was all about, and if someone took you seriously enough to guide you.

This is the present reality: everything is falling apart, nothing gets completed, and nothing makes sense. But worst of all, you know it wasn't always like this. Behind the fog and the darkness there is a vague memory of good times, when you knew where and who you were, when you felt close to others, and when you were able to perform daily tasks with skill and grace; once the sun shone brightly

and the landscape of life had richness and pattern. But now all that has been vandalized, ruined, and you are left in chaos, carrying the terrible sense of a loss that can never be made good.

Once you were a person who counted. Now you are a 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 abandoned forever, left to rot and disintegrate into unbeing.

Key components of the cultural shift in dementia care are outlined in Table 3.

Underlying the ‘old culture’ is a strictly biomedical framework or paradigm to understand the nature of dementia that places it entirely as a neurological issue, neglecting social-psychological aspects. In this way the culture shift parallels the larger conceptual shift from medical to health geography discussed earlier in the chapter. The adherence to this model along with a pervasive ageism in western society is reflected in depersonalizing care environments (physical, social and psychological). Kitwood calls this framework the “standard paradigm,” while Sabat uses the phrase “classical science.” They both contend that this framework, although resulting in much progress in one aspect of dementia (neurological research), tends to fall into blatant reductionism in that it fails to see persons with dementia as, “being defined and understandable in terms of characteristics beyond their presenting symptoms” (Sabat, 2001, p. 13).

On a practical level, for culture change in dementia care to occur, Purveen and Drance (2012) tell us that it requires widespread support from funding agencies, licensing and accreditation bodies such that new initiatives being implemented by these agencies are consistent with this profound change in practice. In other words, care facilities cannot struggle against a larger system that has contradictory values or leadership and that is not committed to change. This all amounts to the fact that although much research has been done, the degree to which culture change is actually observed at any point is inconsistent

Table 2.2 Two Cultures of Dementia Care (from Kitwood, 1997, p. 136)

Old Culture		New Culture
The primary degenerative dementias are devastating diseases of the central nervous system, in which personality and identity are progressively destroyed.	<i>General view of dementia</i>	Dementing illnesses should be seen primarily as forms of disability. How a person is affected depends crucially on the quality of care and the care environment.
It is important to have a clear and accurate understanding of a person's impairments, especially those of cognition. The course of a dementing illness can be charted in terms of stages of decline.	<i>Priorities for understanding</i>	It is important to have a clear and accurate understanding of a person's abilities, tastes, interests, values, forms of spirituality. There are as many manifestations of dementia as there are persons with dementia.
In relation to dementia, the people who possess the most reliable, valid and relevant knowledge are the doctors and brain scientists. We should refer to them.	<i>Ultimate source of knowledge</i>	In relation to dementia, the people who possess the most reliable, valid and relevant knowledge are skilled and insightful practitioners of care, and family members
There is not much we can do positively for a person with dementia, until the medical breakthroughs come. Hence much more biomedical research is urgently needed.	<i>Emphasis for research</i>	There is a great deal that we can do now, through the amplification of human insight and skill. This is the most urgent matter for research.

Care is concerned primarily with providing a safe environment, meeting basic needs and giving physical care in a competent way.	<i>What caring entails</i>	Care is concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting basic needs and giving physical care are all essential, but only part of the care of the whole person.
When a person shows problem behaviours, these must be managed skillfully and efficiently.	<i>Problem behaviours</i>	Most so-called problem behaviours should be viewed, primarily, as attempts at communication, related to need. It is necessary to seek to understand the message, and so to engage with the need that is not being met.
In the process of care the key thing is to set aside our own concerns, feelings, vulnerabilities, etc., and get on with the job in a sensible, effective way.	<i>Carer's feelings</i>	In the process of care the key thing is to be in touch with our concerns, feelings, vulnerabilities, etc., and transform these into positive resources for our work.

(Puurveen and Drance, 2010). Moreover, while some organizations have instituted deep change throughout, others show incremental and/or superficial change and still others have failed to achieve or sustain significant improvements (Doty, Koren, & Sturla, 2008). With that in mind, over the past 20 years, a number of models of care have emerged that embody goals of the culture change movement. Some of these are represented in Table 2.3.

Table. 2.3 Models emerging from the culture change movement
 (Adapted from Purveen and Drance (2012))

Model	Description	Reference
<i>The Eden Alternative</i>	Advocates for fundamental organizational changes & the introduction of natural elements (children, animals, and plants) to the home as part of the creation of a habitat. The primary aim is the elimination of loneliness, helplessness and boredom – described as the three ‘plagues’ of life in residential care.	(Thomas, 1994)
<i>The Wellspring Model</i>	Focuses on employing interdisciplinary resource teams for clinical quality improvement through consultation and education.	(Stone et al., 2002)
<i>The Gentle Care Model</i>	Advocates for the creation of a “prosthetic” care environment (artificially created based on individual needs and talents) for persons living with dementia.	(Jones, 1999)
<i>The Greenhouse Model</i>	Initially conceptualized by Thomas, advocates for small-scale homes, thereby moving away from care in large hospital-like institutions.	(Rabig et al., 2006)

In his book, The Eden Alternative: Nature, Hope, and Nursing Homes (1994), William Thomas laid out the philosophy of nursing home care known as the *Eden Alternative*. Thomas' goal was to deinstitutionalize the culture and environments of long term care facilities by introducing natural elements such as plants and animals and alleviating the ‘three plagues’ of boredom, helplessness, and loneliness (Thomas, 1994). This model is a complete, principle-centred philosophy for culture change, providing a way of thinking and a set of values rather than just a set of operational or programmatic

changes. The ten core principles espoused by the Eden model are found in Table 2.4 as follows:

Table 2.4. The Eden Model Core Principles

1. The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering among our Elders.
2. An Elder-centered community commits to creating a human habitat where life revolves around close and continuing contact with plants, animals, and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.
3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.
4. An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.
5. An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.
6. Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.
7. Medical treatment should be the servant of genuine human caring, never its master.
8. An Elder-centered community honors its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.
9. Creating an Elder-centered community is a never-ending process. Human growth must never be separated from human life.
10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

Adapted from: <http://www.edenalt.org/mission-vision-values>, accessed 5/15/2013.

Initiated by an alliance of eleven non-profit nursing homes in Wisconsin, U.S.A, the *Wellspring Model* has six core elements according to Reinhard and Stone (2001) that, when implemented, results in an increase in the quality of care for the residents. First, an alliance of nursing homes with top management committed to making quality of resident care a top priority. Second, shared services of a geriatric nurse practitioner (GNP), who develops training materials and teaches staff at each nursing home how to apply nationally recognized clinical guidelines. Third, interdisciplinary “care resource teams” that receive training in a specific area of care and are responsible for teaching other staff at their respective facilities. Fourth, involvement of all departments within the facility and networking among staff across facilities to share what works and what does not work on a practical level. Fifth, empowerment of all nursing home staff to make decisions that affect the quality of resident care and the work environment. And last, Continuous reviews by CEOs and all staff of performance data on resident outcomes and environmental factors relative to other nursing homes in the Wellspring alliance. The underlying philosophy of the Wellspring Model is that in each facility, management sets policies for quality, and staff members who know the residents best ultimately decide how to implement those policies. This way, all employees participate in decisions that affect their work and the care of the residents (Stone et al., 2002).

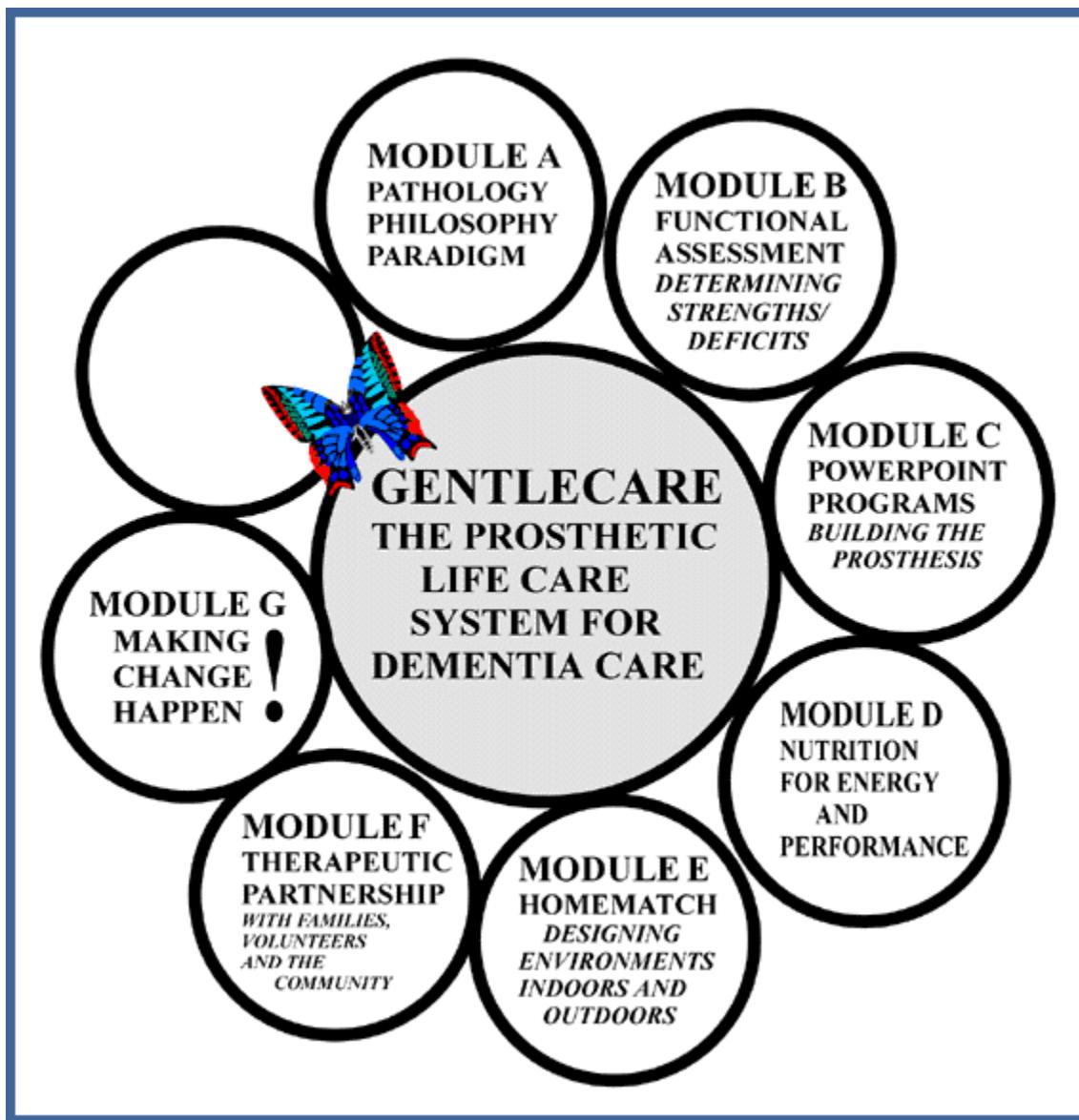
Gentle Care is an approach to dementia care that emphasizes a therapeutic relationship between the person with dementia and the physical environment, the programs, and the care partners (family, staff, volunteers, resident). The resulting ‘prosthetic environments’ (artificially created for each individual) are geared towards the support of each resident’s continuing abilities rather than demanding that the resident

adapt to it and perform in ways no longer possible (Jones, 1999). Its implementation is guided by seven modules that are shown in Figure 6.

Rooted in the tradition of the Eden Alternative, the Green House Model strives to deinstitutionalize long-term care through the creation of smaller, purpose-built residences to replace large institutional facilities. The architecture of these residences is designed to be ‘warm, smart, and green’ (Rabig et al., 2006). The *warmth* is enriched by the decor, floor plan, furnishings and people (6-10 residents/facility). A *smart* facility includes the use of cost-effective and efficient technology such as ceiling lifts and other adaptive devices. A *green* facility offers sunlight, plants/gardens, and access to outdoor space to the residents.

The Lodge at Broadmead has adopted a hybrid of all of these models through extensive research regarding best practice in dementia care. This hybrid model is described in detail in Chapter 3 as it is the site for this research. While these models have distinct characteristics, they have much in common as they share the fundamental values of providing person-centered care in the care giving context, the primary goal of which is to enhance and acknowledge the person with dementia as a unique individual while validating their emotional reality and affirming their lived experience (Brooker, Wooley, and Lee, 2007).

Figure 2.1. Modules for Implementation of Gentle Care



From: <http://www.gentlecare.com/>.

2.6. The case for a person-centred research approach

The culture shift in dementia care is echoed by a methodological shift in gerontological research which has traditionally been dominated by the bio-medical model of health and disease promoted within the ‘old culture.’ In this old framework, an

individual with dementia is viewed strictly as a disease entity, thus their subjective experience is glossed over by an emphasis on tracking the disease process; mapping cognitive and functional decline (Downs, 1997; Hubbard et al., 2003). The work of Kitwood (1997) and others (e.g., Sabat and Harre, 1992) that underlies the culture shift movement, has drawn attention to the importance of respecting the personhood of individuals with dementia, of acknowledging their rights, and valuing their perspectives and experiences (Downs, 1997). As a result, there are calls for a more person-centred approach to gerontological research that include the voices of individuals with dementia as being equally important as those who provide care to those with dementia (Dewing, 2002).

2.6.1 Why include individuals with dementia in the research process?

The following poem was written by a friend of a Church of Scotland minister who has Alzheimer's disease and is living in a residential care facility:

*The wilderness within you has been stripped;
only the graininess is left.
Yet so much intact,
Despite erosion of that sense of self;
So much remaining
Which can cross the chasms
When words get in the way of knowing
-a touch, a smile-
With your engrained benevolence
You make me mindful of what humanness entails.
You have no cogent thought, and yet*

*Your muddled words
 Are full of thoughtfulness.
 I sing for you, and wonderfully
 You join in, add harmony.
 Then shall the tongue of the dumb sing;
 For in the wilderness shall waters break out,
 and streams in the desert.
 I feel as Moses must have felt
 Striking the rock.*

(De Luca unpublished; Adapted from Goldsmith, 2002, p. 24)

This poem represents an interpretation of the essential ‘spark’ (personhood) that remains throughout the neurological deterioration that typically comes with dementia. It sets the presence of a dementing illness within a social, rather than medical context, and thus affirms the possibilities and importance of understanding the person in spite of their neurological incapacities. Furthermore, after interviewing six people with dementia and their family supporters, Keady, Nolan and Gilliard 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” (Keady, Nolan and Gilliard, 1995, p. 15). This bring 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)?

At the broadest level, Wiersma (2008) notes that, “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).

To ensure that policy and practice reflect and respond to the needs of residents with dementia, at the facility level it is necessary to acquire an understanding of their subjective experiences (Wilkinson, 2002). This subjective experience can only be captured through direct engagement with individuals with dementia representing a shift from conducting research 'on' to research 'with' persons with dementia (Cotrell and Schulz, 1993). Furthermore, there is a great deal of evidence that suggests a disconnect between the views of proxies (i.e., family members, caregivers) and those with dementia making it imperative to hear the voices of those living with dementia (Dewing, 2002; Harmer and Orrell, 2008).

While it is necessary to understand the rationale behind including people with dementia in the research process, the more difficult and practical issue is how to accomplish this, especially for those with more advanced dementia.

2.6.2 How to involve individuals with dementia in the research process

Three main issues surround the question of how to involve individuals with dementia in the research process: consent, interviewability, and understanding. Although some research has revealed a potential disconnect between people with dementia and their proxies in the *consent* decision (McKeown et al., 2010), in the event that an individual with dementia lacks the capacity to provide free and informed consent on their own behalf, the use of proxy consent may be considered a more appropriate approach

(Bartlett and Martin, 2002). This approach is based on the belief that the proxy has knowledge of the individual with dementia prior to the onset of dementia and the decision to consent will be based on the individual's best interests. Furthermore, in an effort to bridge the possible disconnect between the individual with dementia and the proxy, it is necessary to seek assent from the individual with dementia prior to each research encounter. Assent is defined as a willingness to participate in the research task at hand (McKeown et al., 2010). In seeking assent before each research encounter, the process of consent becomes grounded in what the individual with dementia is specifically asked to do, and attention remains focused on the individual and where they are at in the trajectory of their dementia rather than just the proxy and the researcher (Hubbard et al., 2002,). Furthermore, consent or assent from individuals 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 (2000) 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 individual's 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 person-centred care as individual's 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. Malcolm 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, interviewed or aided. 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 effects 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.

Researchers have also employed methods that are quantitative in nature to represent the voice of individuals with dementia. These are in the form of instruments that assess various outcomes of facility based care such as person-centred care. As person-centred care is believed to represent current best practice within facility-based dementia care, it is helpful that clinically relevant and reliable instruments be developed for its empirical assessment though few such instrument are currently available (Edvardsson and Innes, 2010). The most established instrument to empirically assess the provision of person-centred care in dementia-care settings is Dementia Care Mapping (DCM; Kitwood and Bredin, 1992). For Kitwood (1997), DCM represents a “serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill” (p.4). Elements of both the quality of the care environment, and the quality of life experienced by individuals with dementia are measured as their interdependence is acknowledged (Brooker, 2005). The underlying premise of DCM is that if personhood is maintained/enhanced within the care

environment, the individual will be observed to be in a relative state of well-being; if not, then a malignant state will be observed. To this end, an observer tracks and records the primary activity and relative state of affect and engagement, of one to six individuals over a pre-determined time period (Brooker and Surr, 2005). Quality of care is gauged by observing and evaluating the interactions between staff and residents, while quality of life is captured through an overall well- or ill-being score for an individual or a group (Brooker and Surr, 2005). With regards to the evaluation of the physical aspect of the care environment, recent work by Chaudhury and colleagues (2011) to develop an add-on environmental assessment component to DCM offers an evidence-based means for identifying environmental features that positively or negatively influence residents' behaviour, mood and/or engagement.

While DCM attempts to analyze care provision from the perspective of the individual with dementia, there is always a potential disconnect between the observed experiences of care, and the manner in which the individual experiences such care (Cheston et al., 2000). Moreover, when employing an empirical instrument such as DCM, the care experience and evaluation is ultimately based on the opinions of the researcher while the resident remains voiceless with respect to their subjective experience. A qualitative, interpretive research approach is necessary to elicit these subjective perspectives from individuals with dementia.

2.7 Summary of chapter

This chapter has aligned the fields of health geography and geographical gerontology with dementia care through a shared recognition of the physical, social and

psychological aspects of the environment and its transactions with the identity of people living with dementia. Specifically, the cultural turn and spatial turn in health geography and geographical gerontology, and the culture shift in dementia care have ushered in a shared concern for place as a multi-layered living entity and health and disease as social constructs. Literature on research methodology that aligns with person-centred care when doing research with people living with dementia was then explored along with some of the main considerations required for this research approach to take place. This will help to contextualize the methodological discussion in chapter 5 and research approach in general. The next chapter will describe the methodology and techniques used in this project to collect and interpret the data.

Chapter 3. Methodology

This chapter provides an in depth description and rationale behind the methodology and approach used to address the research questions. In particular, the specific questions being addressed relate firstly to how a person-centred care philosophy has been implemented in a residential care facility from the perspective of the leadership and staff members, and secondly to considering how an environment that is informed by person-centred care is experienced by residents with dementia. The subjective nature of these questions requires a methodology that employs interpretation and reflexivity on the part of the researcher. The chapter is organized as follows: the philosophical orientations and methodological approaches are described to bring to light the foundations upon which the information gained is to be understood; the study site, research participants, and recruitment system employed to gain access to participants are then laid out followed by the specific research methods and analysis techniques used to collect and interpret information from participants. Finally, the limitations of this project are outlined along with the main methodological challenges encountered. Throughout this chapter the researcher is recognized as being embedded in the research context through sections that describe the nature of relationships to the people and places under study.

3.1 Philosophical and Methodological Orientations

This exploratory and interpretive study sets out to understand the unique perspectives and experiences of person centered care by the people who work and reside in a residential care facility in Victoria, B.C. The lodge at Broadmead is considered innovative in its approach and represents a strong push within the overall cultural shift in

dementia care. The focus in this research is on meaning and lived experience with respect to this particular environment in relation to the individuals who live and work there. It is not helpful to appeal to any universal understandings of the phenomena or to emphasize replicability and statistical validity. Rather, the emphasis is on subjective and situational truths, partial knowledge, and perceptions consistent with the tenets of qualitative research (Thrift, 2010; Morse, 1994; Cook and Crang, 1995). Thrift (2010) tells us that, “What makes a study qualitative is that it relies on inductive reasoning processes to interpret and structure the meanings that can be derived from data” (p. 64). This implies that rather than the deductive process of ‘hypothesis testing,’ qualitative research can rely on the data itself to generate hypotheses.

Qualitative research includes a wide range of philosophical orientations, methodological approaches, and analytical operations. In her summary of the cognitive processes involved in qualitative research, Morse (1994) reveals that all qualitative analysis, regardless of the specific approach, involves: *comprehending* the phenomenon under study, *synthesizing* a portrait of the phenomenon that accounts for relations and linkages within its aspects, *theorizing* about how and why these relations appear as they do, and *recontextualizing*, or putting the new knowledge about phenomena and relations back into the context of how others have articulated the evolving knowledge (Morse, 1994). This chapter and the previous two chapters establish the context for the study, while the following three chapters will synthesize the relevant findings, appeal to geographical concepts to understand the findings from a new perspective, and recontextualize the information to draw conclusions based on theories generated from the data and existing theories in the literature.

Qualitative research aims at producing and/or uncovering inter-subjective rather than absolute or universal truths. As Cook and Crang (1995) argue, “it is the ways in which people make sense of the events around them, and render these ‘true’ in their own terms that is most revealing about how their/our lives are embroiled in larger social, economic and political processes” (p. 11). The social world, then, is (re)created/constructed rather than being simply mirrored through stories told in the research process. Furthermore, the orientations of the qualitative researcher that are shaped by his/her values and interests cannot be separated from the findings. This idea is summed up in Schuman’s (1982) assertion that, “artifacts are in the mind of the beholder” (p. 23). In other words, social researchers are part of the social world they study, giving social research its reflexive character. As a result, it is important for me as the researcher to constantly reflect upon my positionality within the research process and to aim to understand how that affects the data and analysis.

This research is influenced by a post-modern ontological orientation that was ushered in by the cultural turn in human geography (Jackson, 2010). From this orientation, the salient concepts of place, disease, and health are all viewed as situational and as social constructs that emerge only in and through individual experiences of the world rather than as pre-determined, universal entities. The aim is to gain an understanding of the experience of a specific group of people in a specific context, apply this understanding to relevant theories in human geography and create a localized ontology.

This is a qualitative research project concerned with understanding the subjective human experience of life in a specific social and spatial context, and over a particular

historical time (Thorne, 2011). Knowledge is partial and always situated within its context. Therefore, the search is not for universal truths but rather for subjective understandings of a particular phenomenon where the researchers as well as the subjects are embedded in the social and cultural relations under study (Cook and Crang, 1995). As Cook and Crang (1995) note, "stories told in the research encounter are not simply to be regarded as a means of mirroring the world, but as the means through which it is constructed, understood and acted upon" (p. 11). Rather than looking for the 'absolute truth', this project aims at producing inter-subjective truths that reveal how people make sense of events around them and render them 'true' in their own terms. Inter-subjectivity implies that the researcher is intimately involved in knowledge production as the data must pass through his/her interpretive lens and context as well.

3.1.3 Methodological Approach: Ethnographic Case Study

As Hancock and Algozzine (2006) note, case studies are, "intensive analyses or descriptions of a single unit or system bound by space and time" (p.9-11). The case study is viewed as the object of study allowing for various methods to develop an in-depth analysis of phenomena that are inseparable from their context (Cresswell, 2007). Through the use of various methods and the collection of data from the perspectives of multiple actors this methodology will help to provide an in-depth analysis of a specific environment with respect to the meaning for those involved. Employing an ethnographic approach to the case study at TLAB allows me to analyze the subjective experiences of different groups of people (including myself, as the researcher) that are interrelated to each other through their roles in TLAB in an effort to gain an understanding of the implementation of a person-centered approach to care.

Although a strict ethnographic approach wasn't taken, this project contains many aspects of ethnographic research. Hammersley and Atkinson (1983) view ethnographic research as that which, "involves the ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light on the issues that are the focus of the research" (p. 1). This project involves reconnaissance in the form of volunteer work, and face to face interviews with staff, management and a resident to explore the implementation and experience of person-centred dementia care as a social, physical, and psychological phenomena. Ethnographic research methods strive for greater depth of information (i.e., thick description) and not as much emphasis on breadth of coverage. Cultural relativism is pursued in ethnographic research instead of universal truths, and is thus an appropriate approach for the philosophical orientation I have adopted (Johnston et al., 2009). The ethnographic researcher, "portrays people as constructing the social world, both through their interpretations of it and through actions based on those interpretations" (Hammersley and Atkinson, 1983, p. 11). Furthermore, the researcher cannot exist independently of the social phenomena in question. Knowledge is only obtained through the subjective lens of the researcher based on his or her interpretation of data. This project is aimed at a deeper understanding of the attitudes and behaviours of different social groups in the same locality in an effort to gain a rich and nuanced understanding of the experience within that care facility.

The concepts of theoretical sampling, theoretical saturation, and theoretical adequacy are important to ethnographers as alternative measures to validate truth claims

(Cook and Crang, 1995). Theoretical sampling is a sampling technique that strives for quality in samples as opposed to focusing on the quantitative representativeness of the number of samples (Cook and Crang, 1995). Theoretical adequacy accounts for the fact that it is not always practical or necessary to research the lives of every member of every interest group in a research project. Theoretical saturation indicates that there comes a point in the research process where the range of arguments that can be made regarding the subject have been made. At this point the researcher should either move on to analyze this information or seek out the viewpoints of a differently positioned group rather than seeking more members of the same group (Cook and Crang, 1995). Theoretical adequacy is a goal for ethnographic researchers, achieved through the exploration of multiple perspectives as well as multiple methods to gain a more rounded picture of the research problem.

3.2 Ethical considerations and approvals

This project required two ethical approvals to proceed. The first approval was from the University of Victoria Human Research Ethics Board. Approval at this level was conditionally granted, contingent upon approval from TLAB's internal review proces by its Board of Directors. At each stage of the ethical review process, approval was granted with the condition that I share my findings with the research facility in the form of an oral presentation upon completion of the write-up. Research that involves a vulnerable group such as those living with dementia requires careful ethical considerations to minimize the potential to cause harm to the participants. To account for this vulnerability, I consulted with leadership and staff at TLAB who provided many recommendations about how to

gain access to the residents as well as how to engage in conversations in a way that would not agitate them. Of most concern in the University of Victoria's ethics process was the ongoing consent from the research participants that are living with dementia. As this group was assumed to lack the capacity to give their own consent, I sought consent by proxy through their primary healthcare representatives. Additionally, assent was sought during the interview encounter to ensure that the resident was willing at the time of the interview. For the staff and leadership interviews the major ethical issue was maintaining the confidentiality of participants. Careful proofreading also occurred to ensure that use of quotes does not inadvertently identify an individual participant. The presentation of research findings from the staff and leadership in a thematic format, rather than using individual narratives, for example, is another confidentiality safeguard. This approach may also serve to reframe the discussion so that any information that is shared does not reflect a specific individual, but instead speaks broadly to the environment at TLAB as a whole. Of particular interest here is the idea that although participant observation (direct use of data collected) during the volunteer period was approved by the University of Victoria Ethics Committee, TLAB's internal reviewers viewed this as a breach of privacy. Together we decided that, since this would require consent from every resident that I came in contact with, I would use the information in a different way. Moreover, it was important that I focus on my role as a volunteer when acting in that capacity and focusing on collecting data may have taken away from this ability. Volunteers play an important role at TLAB in helping to relieve the burden of the care aids and for me to be focusing on my research when in this role may have effectively decreased the quality of life for the residents.

3.2 Study Site: the Lodge at Broadmead (TLAB)

In this section, the study site is introduced and described. It goes on to describe the specific dementia care framework and guidelines that have been adopted by this facility in its efforts to create a person-centred environment. This information, along with setting the stage for information collection, analysis and discussion, contextualizes TLAB's dementia care framework within the breadth of approaches that have embraced the culture shift and guidelines of person-centred care described in chapter 2.

The Lodge at Broadmead (TLAB), opened in 1997, is a non-profit, residential care facility located in Victoria, British Columbia. It is managed by the Broadmead Care Society, run by volunteer board members responsible for governance; the chair of whom reports to the Chief Executive Officer (CEO). Base operational funding comes from the Vancouver Island Health Authority (VIHA), which is allotted a certain amount of funding from the British Columbia Ministry of Health. TLAB is funded at 3.24 hours of care per resident per day (Robinson, 2007).

TLAB houses approximately 225 people with an average age of 85, more than half of whom are Veterans and approximately 75 percent of whom have moderate to severe levels of dementia, and all need 24 hour care (Robinson, 2007). As a result, the conceptualization and implementation of the Dementia Care Program (DCP) in 2003 is of great importance to account for the increasingly complex care needs of this resident population. Although its tenets are applied throughout TLAB, the DCP was created to account for residents whose primary diagnosis is dementia. The DCP is still used as a framework for care provision in a move toward a more person-centered approach to care.

Supplementary funding for the DCP comes from Veteran's Affairs Canada as part of their National Dementia Care Initiative (Gnaedinger and Robinson, 2010).

3.2.1 My introduction to TLAB

I was introduced to TLAB through a discussion with a friend who has a family member that is a resident there. After I explained that I was interested in studying person-centred dementia care, he directed me to TLAB as a facility that I may be interested in looking into as an application of this philosophy of care. After meeting with the Director of Care and the Clinical Nurse Specialist I found that they were very supportive of this type of research and were willing to afford me access in a research capacity. I had a brief tour of the facility and based on the supportive, knowledgeable and passionate leadership; home-like built environment; and explicitly person-centred philosophy of care, decided that I would move forward with research at this site pending appropriate ethics approval and approval from the leadership at TLAB. Additionally, having already visited eight other possible facilities, and having read TLAB's internal evaluation reports (e.g., Gnaedinger and Robinson, 2010) it was clear that this facility was doing something right in terms of the quality of the environment and is perhaps situated at the more evolved end of the spectrum when it comes to the provision of person-centred care.

3.3.2 TLAB's institutional framework for person-centred care: The Dementia Care Program (DCP)

The development of the existing dementia care program (DCP) at TLAB was led by the Clinical Nurse Specialist who engaged clinical leaders, internal TLAB employees and recognized experts to reflect on current practices and apply them to identify new approaches to dementia care at TLAB (Robinson, 2007). The DCP includes five main

components: renovations to the built environment, interdisciplinary staffing, developing the “Dementia Care Clinical Program” to provide clear goals and guidelines for care delivery, extensive and ongoing education for the staff to optimize their knowledge and skills, and continual evaluation (Gnaedinger and Robinson, 2010).

3.3.2.1 The five components

Renovations to the *built environment* were undertaken in an effort to, “improve the quality of care and of life for [residents] with dementia in ways that reflect a new awareness of the impact of the built environment on persons with dementia” (Gnaedinger et al., 2007, p. 1). To this end, one 32-bed lodge was separated into two smaller lodges, one housing 14 residents, and the other 16 residents (Palm North and Palm South, respectively). These new lodges along with the Magnolia lodge (an existing 13-bed lodge) were built to accommodate ambulatory residents whose primary diagnosis is dementia with the general recognition that, “fewer people in one dwelling, reduced noise and a calm, home-like atmosphere are known to contribute to better functioning and quality of life for residents with dementia” (Gnaedinger, et al., 2007, p. 1).

To supplement the decrease in size, each lodge was furnished with new home-like kitchens, living rooms and dining rooms. Murals with familiar scenes are hung in the common areas and on the exit doors; non-institutional finishes and furnishings such as natural wood and domestic upholstery were added; a new team centre for the nurses separate from the residents' living area; and silent resident call systems were incorporated. The silent call system is said to minimize unnecessary noise and promote safety and privacy for the residents (Gnaedinger et al., 2007). Moreover, each of the three

lodges has easy access to a courtyard that contains a garden that can be used for outdoor activities.

With the funding provided by Veterans Affairs Canada, TLAB hired a number of *new, interdisciplinary staff members* from multiple disciplines to work on the renovated lodges as well as a full-time clinical nurse specialist to lead the DCP. These new staff included a second full-time activity worker, a full-time rehabilitation assistant, a half-time social worker and a half-time occupational therapist (Gnaedinger and Robinson, 2010).

The *Dementia Care Clinical Program* is a clinical practice guideline created by the clinical nurse specialist in consultation with nursing leaders and a cross-section of staff at TLAB that is based on best practices in dementia care (Gnaedinger and Robinson, 2010). The following list shows the twenty best practice principles that were identified by the interdisciplinary team at TLAB through a review of guidelines, standards, and position papers from Alzheimer organizations around the world:

- Person-centred care
- Flexible scheduling of care provision
- Having a philosophy of care
- Consistent staffing
- Interdisciplinary assessment, including life story
- Regular interdisciplinary reviews
- An interdisciplinary care plan in place that supports a consistent approach to care provision
- Staff are educated and trained in dementia care
- Small number of people living together with limited distractions
- Medication optimization
- Focus on retained abilities

- Acknowledgement of previous skills
- Familiarity of environment (including staff)
- Family support and involvement
- Use of environment as a therapeutic psychosocial tool
- Meaningful activities are provided
- Least restraint policy
- Pain assessment and management
- Behaviour management guidelines in place

These principles went on to become the foundations of the Dementia Care Clinical Program, which is further organized around practice recommendations in six key areas: organization, resident assessment, family and friends, care provision, environment, and education. These recommendations are utilized in an effort to realize the fundamental goal of the DCP as stated by Gnaedinger and Robinson (2010), “to ensure excellence in person-centered dementia care” (p. 89) or more broadly, to improve the quality of life for everyone involved and quality of care for the residents (Robinson, 2007).

Dementia care *education* is an integral part of the DCP. At TLAB, this education has mainly taken the form of two-day workshops delivered to staff and leadership in all roles.

The first workshop, titled Supportive Pathways, focuses on best practices in person-centred dementia care. This workshop is offered three times per year in-house by specially trained staff, and is reinforced by a one-day refresher course created by the clinical nurse specialist that is delivered regularly to all staff members after they complete the initial workshop. The Supportive Pathways two-day workshop was adopted by TLAB from Carewest, and “covers content ranging from personal and organizational beliefs and

communication, to disease processes and responding to altered behaviour" (Robinson, 2007, p. 25). All staff are scheduled to attend this workshop after they have completed their probationary period. This ensures the development of facility-wide knowledge of best practice and skills to care for people with dementia as well as promoting the ongoing learning about person-centred care within TLAB.

The second major education initiative, titled The Dementia Difference, was developed in response to the aging resident population and in particular those with dementia. Its overall goal is to, "increase TLAB's staff members' capacity to provide excellent care until death through the application of palliative principles, specifically focusing on issues that are unique to caring for people who are dying with dementia" (Gnaedinger, et al., 2010, p. 2). The specific objectives are to promote a better understanding of the process of dying among staff members, to enhance residents' experience, comfort, dignity, warmth and feeling of being at home while dying, and to ensure that families experience consistent, competent, and coordinated end-of-life-care (Gnaedinger, et al., 2010).

These formal educational sessions help to create an atmosphere of constant learning and development as well as making sure that all of the staff have an understanding of, and ability to implement, best practices in person-centred dementia care.

Since 2004, each component of the DCP has been *evaluated* by an external consultant. Methods have included surveys for staff and family members, group interviews and one-on-one interviews. An example of one major evaluation is a retrospective survey conducted in 2009 of all the staff members who had worked

continuously at TLAB throughout the five years since the DCP was implemented. The purpose was to answer the question of, “Are we moving towards excellence in person-centred dementia care after five years of DCP implementation?” (Gnaedinger and Robinson, 2010). The findings included three substantial transitions in care as delineated by the staff: a shift in focus of care from tasks to residents; an increase in intra-team and interdisciplinary familiarity, communication and teamwork; and an increased amount of knowledge and understanding of dementia and dementia care from staff and leadership in all positions (Gnaedinger and Robinson, 2010). These findings seem to directly reflect the best practice principles upon which the DCP was based. This same evaluation also reports four factors that may be impeding person-centred dementia care: fiscal restraints, increasingly complex care needs, resistance to change from more experienced staff members, and the use of on-call staff (Gnaedinger and Robinson, 2010).

3.3 Profile of Participants

This section introduces and describes the three groups within TLAB that are involved in the research along with any prior relationships I have with them. These relationships helped to inform the research in many ways including shaping my perspective on the information gained and building trust within the facility that helps with rapport during the interviews.

3.3.1 My Relationship with Participants

Prior to, and throughout, the research process I met with the Clinical Nurse Specialist, Janice Robinson, who greatly influenced the conceptualization and implementation of the project. As a gatekeeper, Janice provided me with invaluable

information about TLAB, helped to inform me of possible research participants, and facilitated my access to the eventual participants through recruitment. Furthermore, through my volunteer work at TLAB (discussed further in section 3.5.1), I formed meaningful relationships with many of the residents in Palm North, and working relationships with some of the staff members. These relationships contributed profoundly to my perspective on the environment (see reflexivity section that describes the myriad of influences that shaped my perspectives) and also helped to facilitate my access to participants. As well, having this prior relationship with the resident participants reduced the risk of agitation, allowed for more information to be shared and helped to develop my interpretations.

3.3.2 Residents

The main challenge I encountered throughout this project was gaining access to residents as research participants. My goal was to speak with 3-4 residents on Palm North (where I had been volunteering and therefore had formed relationships with some residents). The possible participants here all had moderate to severe cognitive impairments brought on by dementia. I selected this group with the help of the Clinical Nurse Specialist based on my experience with them as a volunteer as well as considerations about agitation (i.e. historically easily agitated residents would be excluded as I did not want to be too invasive). As their diminished cognitive capacity rendered them less able to give verbal consent to participate, I sought proxy consent from their primary health care representatives (additionally, assent was sought at the beginning of the interview with the resident). To that end, a letter of invitation (Appendix A) was

sent out to the primary health care representatives (typically family members) of ten of the fourteen residents on Palm North instructing interested parties to contact me. A consent form (Appendix B) was provided to be signed by the representative if they agreed to the interview.

Ultimately, I was only able to interview one resident. This person is a female resident who I am calling Jane, a pseudonym. Jane lives on Palm North and has a primary diagnosis of dementia with advanced cognitive impairment. She is a wonderful candidate for many reasons but particularly for her social demeanour. I had spent some time with her as a volunteer and we had a strong connection whether sharing a cup of hot chocolate or walking around Palm North. She was able to share many stories about her life with me through artifacts around the Lodge such as books, magazines and pictures. My meaningful relationship with this resident developed over four months of interactions. In addition, her primary healthcare representative (her daughter who I will call Linda, also a pseudonym) was one of the few members of this group who came forward and agreed to meet with me. Overall, the most common reasons I was given for refusal to participate in the study were concerns about safety for the residents and family members' perceptions of the inability of their loved ones to communicate effectively. The profound implications of these types of responses are discussed further in chapter 5. In contrast, Linda was very supportive of this research and her mother's participation in it. Discussions I had with Linda about her experiences in TLAB and other facilities, as well as her personal experiences with dementia, were enlightening. Though they are not directly a part of this research, these discussions had a profound influence on my perspective of TLAB and dementia care.

3.3.3 Leadership

Leadership refers to those people whose role it is to create and implement dementia care policy initiatives and who don't necessarily work directly with the residents (though in practice they all do). Five members of the leadership team at TLAB were recruited purposefully and interviewed based on their leadership role as defined by this project, each representing an area of expertise within TLAB and dementia care in general. As well, they needed to have been at TLAB long enough to have engaged with the DCP. The decision of who fit these criteria was made through discussions I had with the Clinical Nurse Specialist at TLAB who helped identify candidates and then sent out internal emails containing a letter of invitation (Appendix C) to all of the candidates selected. Having the invitation sent out internally was very helpful as it showed that the project was supported by the facility. Interested candidates were then directed to me to schedule the interview.

3.3.4 Staff

This group was defined as those individuals whose main role in TLAB is to work directly with residents or who work at TLAB but don't necessarily influence policy directly. Initially, a facility-wide letter of invitation (Appendix D) was sent out internally by the Clinical Nurse Specialist to gauge interest. This was not successful (yielded two interviews) most likely due to hectic work schedules. As a result, I consulted with the Clinical Nurse Specialist to narrow down the candidates based on specific roles within TLAB in an effort to capture a broad spectrum of perspectives while personalizing the invitations. Personalized invitations were then sent out to staff members who had been purposefully chosen to represent a specific area of expertise in their role. In sum, ten staff members were interviewed either in the form of one-on-one interviews, or interviews with two participants together.

The specific roles of the staff participants covered the areas of care aides, activity workers, occupational therapists, environmental services, social workers and Licensed Practical Nurses- spanning a broad spectrum of roles and perspectives. Although I intended to focus this project on the areas built specifically for dementia care (Palm North/South, Magnolia), the staff participants worked in various areas of TLAB. This tension is reconciled by the idea that although these lodges are the only ones built specifically for people with dementia, person-centred care is espoused as a facility-wide philosophy and all staff have been trained and educated about best practices in dementia care. Furthermore, all of the participants had had direct experiences in the dementia-specific lodges.

3.4 Research Procedures

This section contains information on the specific research procedures that were used for each group, beginning with reconnaissance in the form of volunteer work. This initial step helped to shape my perspective of the environment as well as introducing me to and informing me of some of the research participants.

Eleven semi-structured interviews were conducted with a total of sixteen participants, all of whom are a part of TLAB's team either in a leadership, staff, or resident capacity. Three of these interviews took place with multiple participants. These interviews took place with five leadership members, ten staff members, and one resident, revealing a range of perspectives that provided a rich source of data for this study.

3.4.1 First: Reconnaissance

Before conducting any interviews, I visited TLAB once a week for four months as a volunteer for 2 hours at a time on average. Specifically, my role was as a Lodge Assistant in the Palm North Lodge, one of the purpose-built lodges for residents whose

primary diagnosis is dementia. My duty was simply to spend time with the residents in whatever way was meaningful to them. Sometimes this meant simply sitting with them quietly and other times it meant engaging in conversations or activities with them such as reading a magazine or walking around the Lodge. In this capacity, my role was to relieve some of the stress placed on care aides and nurses.

Initially, my main reason for volunteering was to gather as much information as I could about the residents and the environment through reflections at the end of each shift written in a research journal. Indeed, this experience was integral to my understanding of the physical, social, and psychological aspects of the environment at TLAB and, as such, helped frame my perspective of the environment and helped me decide who I wanted to speak to and to consider what I would ask each of them. These insights also provided me with some context about how to interpret my findings. As time passed I found that I began to form meaningful relationships with some of the residents that I will always cherish. With the help of these residents and the staff members in Palm North, I began to understand how to approach communication with people with dementia in a way that is meaningful for both me and the resident. The main struggle when communicating with the residents was not their cognitive impairment, but my expectations about how conversations and meaningful interactions should transpire. As I allowed myself to be creative and patient in conversation, and to go with the flow in my interactions with the residents, I felt a greater connection and comfort level in the environment. The residents could feel this new level of comfort, and as a result, began to share their stories with me (though not always with words and often through body language and tone of voice). I felt that these communication strategies helped me conduct the interview with the resident,

and in general, they allowed me to connect on a deeper level with a range of residents with whom I worked.

As well as helping me form an impression of the environment, and allowing me to develop more meaningful relationships with the residents, the volunteer work introduced me to many of the staff members who supported me throughout the research process by introducing me to residents, helping with my communication skills with the residents, assisting me in getting acclimated to the environment, and eventually participating in this project directly through interviews. For all of these practical reasons along with the overall satisfaction of having contributed to the quality of life of the residents and making the lives of the staff a bit less stressful, the volunteer work was an extremely important aspect of this project as well as a personally rewarding endeavor.

I also had the chance to attend a one-day Supportive Pathways educational session. This gave me additional insights into the values and skills being espoused through this program and throughout TLAB. It also provided helpful communication skills that I would employ in my volunteer work and in the research encounters afterwards.

3.4.2 Resident Interview

The single resident interview that I was able to complete with Jane took place mainly in the kitchen of Palm North Lodge where we were able to sit down with hot chocolate in a comfortable environment. Linda, her daughter, who provided consent by proxy, chose to be present throughout. This would prove to be extremely helpful as she was able to connect with her mother in a way that I could not and this resulted in an outpouring of incredible stories told by Jane; stories which gave me a greater

understanding of her historical context. Furthermore, Linda helped to put statements into context thus clarifying the personal and historical reasons underlying statements that could have been confusing for me to interpret from my own perspective alone.

The goal of this interview was to better understand Jane's perspective on, and relationship with, an environment informed by person-centred care. As noted, although I could only gain access to one resident, the perspective gained was invaluable. Often the views of those living with dementia are not available for reasons discussed in chapter 2. Furthermore, this ethnographic research project strives for deeper understanding of subjective and localized perspectives rather than generalizability, making the quantity of samples less important than their quality. Initially, this interview was to be semi-structured, and directed by the interview guide (Appendix E). This guide encompasses a few simple questions regarding Jane's relationship with, and experience of, the environment. In practice, I found even these questions to be too rigid for successful communication with Jane. In fact, it was only once I let go of the research process altogether and truly began to listen as a person that I understood how meaningful this interaction could be. It became more important that I was comfortable with Jane and had a relationship with her through my volunteer work, than being driven by my need to get answers to calculated and pre-conceived research questions. This relationship, as well as the help from Linda, allowed me to go with the flow of communication, and in doing so, I became involved in a symphony of words first? whose meaning could not be accessed through a set of rigid questions asked by a disconnected, detached researcher. As a result, this interview appeared more like an interaction I would have with this resident during my volunteer work, except with facilitation help and clarification from Linda. This is an

important point but it is not clear what you really mean here; needs elaboration how was it the same? Outside of the formal interview process.

This interview was recorded by hand during and immediately after the research encounter as it consisted of fewer words than the rest of the interviews (though just as much data). Conversations were recorded as well as emotions and reactions to capture the nuances of the exchange. The entire interview lasted an hour.

3.4.2.2 Leadership and staff interviews

The ten interviews with leadership and staff were all tape recorded, transcribed and analyzed by hand. The duration of these interviews was approximately an hour, which allowed for rapport to be built and in depth discussion of the salient topics. In many cases, I had already been introduced to the participants either through my volunteer work, the Supportive Pathways session I attended, or from prior meetings to discuss my research. With these participants, the interviews were particularly fruitful as they flowed more naturally with little need to explain who I was and why I was there. The goal of these interviews was to gain understanding of staff perceptions about how the person-centred philosophy of care is conceptualized and operationalized from their differing perspectives.

Interviews with leadership took place in their individual offices, occurring upon participants agreeing to sign the consent form provided (Appendix F). These interviews were semi-structured, generally following the interview guide (Appendix G). However, this group is extremely knowledgeable and passionate about dementia care at the theoretical as well as practical level and, as such, often went beyond the scope of the interview guide opening up new topics to be discussed in later interviews. This was the first group to be interviewed as I wanted to begin with more theoretical and structural

understanding of the environment and gradually move towards more practical understandings with the staff and residents. In the end, leadership and staff members were all able to discuss TLAB on many levels. Ultimately, I believe that the order was not an integral consideration due to my volunteer work which had given me a broader insight into the context.

Interviews with the staff took place in an interview room in TLAB. They occurred during work hours for which the staff were being paid. This shows tremendous support from the leadership and created a relaxed environment. The interviews were semi-structured where participants were again asked to sign a consent form (Appendix H), and following the interview guide (Appendix I). For efficiency, three of these were interviews with two participants each. These created an atmosphere that was more informal than the one-on-one interviews as often the participants would begin to talk amongst themselves and collaborate on responses. As person-centred care is a philosophy which is said to apply to everyone in TLAB, the various staff member perspectives allowed me to gauge the similarities and differences in understanding of this philosophy throughout TLAB.

3.5 Data Analysis and Interpretation

This section begins by locating me, the researcher in the data analysis process in an effort to contextualize my representations of the information gained. It goes on to outline the specific analysis technique that was employed for this project.

3.5.1 Reflexivity

Mauthner and Doucet (2003) argue that, "as researchers we need to be reflexive about, and articulate, the ontological nature of subjects and subjectivities we are using in our research as well as the epistemological assumptions underpinning our methods of data analysis and knowledge construction" (p. 416). This need for reflexivity arises from

post-modern critiques that increased awareness about how knowledge is acquired, organized, and interpreted as relevant to the knowledge claims that are made. Denzin's (1997) dual 'crisis of representation and legitimization' faced by researchers arises from the post-modern recognition of the partial, provisional, situated, and perspectival nature of knowledge claims. Furthermore, "there is an assumption built into many data analysis methods that the researcher, the method, and the data are separate entities...most methods continue to be presented as a series of neutral, mechanical, and decontextualized procedures that take place in a social vacuum" (Mauthner and Doucet, 2003, p. 414). This leads to a tendency for qualitative researchers to simplify the complex process of representing the voices of respondents as though these voices speak on their own, rather than through the researcher who makes choices about how to interpret them (Reinharz, 1992). To reconcile the post-modern crisis of representation and legitimization by locating myself as the researcher in the data analysis process, I will employ Mauthner and Doucet's (2003) reflexivity framework. This framework includes factors of social location and emotional responses, academic and personal biography, and institutional and interpersonal context.

3.5.1.1 Social Location and Emotional Responses

Following from Mauser and Doucet (2003), I aim to locate myself socially and emotionally to help to retain some grasp over the blurred boundary between the respondent's narrative and my own interpretations. In addition, I recognize that these emotional reactions themselves constitute sources of knowledge (Mauthner and Doucet, 2003).

To account for my emotional responses in the analysis process, I employed the

'worksheet' technique. For this, I read each transcript, reflecting on how I was responding emotionally to my participant's (Gilligan et al., 1990). These thoughts are then laid out beside the participant responses allowing me to examine how and where some of my assumptions and views might affect the interpretation or write-up.

As a twenty six year old male Master's student I have not directly experienced either dementia or living in a residential care facility. So, there is a large social gap between me and Jane, a ninety year old female with advanced dementia living in a residential care facility. This gap influenced my interpretation of the interview as my understanding of aspects of her stories was limited. Much of this understanding would have to be based on my understanding of dementia and dementia care, which is largely based on the conceptualizations of Tom Kitwood. This view is premised on ideas about the continuity of personhood and the self throughout the disease process until death. However, having already spent many hours with this resident and forming a meaningful relationship through my volunteer work, I was able to bridge this epistemological gap. Moreover, the presence of her daughter helped to clarify some of the specifics around certain stories that I could not relate to or easily understand.

I am also not a staff member or leadership member at TLAB and have not directly experienced these roles. Again, my volunteer work gave me a glimpse of the experience of the environment at TLAB and, as such, helped bridge the epistemological disconnect (I was better equipped to understand their perspectives).

3.5.1.2 Academic and Personal Biography

I came into this MA program from a background in human geography and philosophy where I was specifically interested in post-modern and post-structural

critiques on the nature of knowledge and of its acquisition. In particular, I was interested in how these critiques seemed to expose issues of social and spatial inequality by questioning and deconstructing the universality of claims to knowledge. This post-modern bent largely informed my decision to study and think critically about the constructs surrounding a marginalized group as well as the methodological decision to invoke qualitative, interpretive approaches to the inquiry. Furthermore, as my academic history mostly consists of theoretical considerations rather than practical ones, I tended to spend more time thinking about theoretical issues brought up in the transcripts and pushed harder for theoretical insights throughout the research process.

My choice of academic texts that guided this research were also affected by my personal biography and this combination of personal life and academic texts led me to particular ways of seeing and hearing during the data analysis process. In particular, the close relationship that I have with the older adults in my own life (e.g., as above) have ultimately affected my interpretation of the transcripts. Respondents who challenged clinical and biomedical conceptions of aging and dementia were given particular weight during the analysis process partially because they resonate with me and my relationships with the older adults in my life as well as with the theoretical literature I had been exploring.

3.5.1.3 Institutional and Interpersonal Context

I was drawn to this work partially for intellectual and personal reasons, but also for pragmatic ones shaped by institutional constraints. In a Social Sciences faculty dominated by quantitative and positivistic approaches, I especially valued input from my supervisor and committee members. Institutional expectations helped to shape this project through time constraints which limit the potential for reflexivity and resources

such as research methods seminars. These helped to shape the methodological, theoretical, epistemological, and ontological aspects of my thesis.

3.5.2 Data Analysis Technique: A 'Rules and Units' Approach

I employed a 'rules and units' approach to the data analysis. This generally consists of breaking up the data collected into similar conceptual units and organising these units into 'maps of meaning' which relate them in a world view or culture (Cook and Crang, 1995; Miles & Huberman, 1984; Miles and Huberman, 1994). This is definitely a challenging area in the research process. The end product does not do justice to the messiness of the analysis process. In reality, the analysis of ethnographic data is, "a messy, ambiguous, time-consuming, creative, fascinating process" (Marshall and Rossman, 1989, p. 112). Reliability is supported by creating a 'paper trail' of notes and revisions which explicitly show the reasons for a particular interpretation and the cognitive leaps towards an interpretation. This aspect was supported by a research journal audit trail throughout the process.

3.5.2.1 Preliminary Work

The primary data consisted of typed transcripts, field-notes from each interview encounter, and field notes from the volunteer observation period. I began by reading through the transcripts one line at a time, attempting to reconstruct the events that each line is referring to. As I read, I wrote in the margins what I thought the meaning and intent of each main statement might be. This process of open coding was supplemented by reading the field notes from the interviews alongside the transcripts, thus giving me a

deeper understanding of the meaning of statements. After completing an entire 'cycle' of open coding, I began to group similar themes together using colored highlighters. These themes became categories which were 'firmed up' by writing them down on a separate piece of paper to make sure I didn't forget them, giving them appropriate labels, and seeing whether there were any similar categories that could be amalgamated.

Additionally, at this stage, I attempted to separate the emic (insider's view) from the etic (outsider's view) categories in an effort to avoid imposing an outside set of categories on the inside perspectives and experiences. However, as Cook and Crang (1995) note, "it is virtually impossible for the researcher to banish all of his/her prior thoughts from the analysis, since his/her research will have been based around a theory-driven selection of participants, and because even noticing an 'emic' code will have required interpretation" (p. 82). Thus, instead of artificially separating these two perspectives, I was conscious of the general drift from emic to etic throughout the coding process by continually asking questions about the extent to which the information reflects the participant's worldview or some composite of my representation of his/her worldview.

I then placed each code on a separate index card and recorded the location of each occurrence in the transcripts. This allowed me to focus the analysis on the ways in which these individual statements relate to each other. Additionally, I compiled theoretical notes throughout this initial coding process that included my hunches and insights about how these codes might relate to each other as well as why they were deemed important at the outset.

3.5.2.2 Secondary Materials

After grouping the cards into piles that seemed to overlap with respect to the

subject matter/topic (i.e., physical environment, social environment, attitudes, values, roles), I began to conceptualize the links between them as well as the major themes within and between piles. This was an iterative process that involved continually comparing the topics to my theoretical notes and primary materials, and drawing conceptual diagrams until each topic could be related to some key issue. An overall code map was created that showed the interrelationships between the themes from general codes such as aspects of the environment to more specific ones such as roles within these aspects of the environment.

These key issues formed the dimensions of the analysis and though they could be considered an insider's perspective, they are shaped by the interview questions which were created with the research purpose and theory in mind. As Bennet and Shurmer-Smith (2002) point out, "writing case studies...is not about truth in the singular, but about partial truths and multiple understandings" (p. 207). The data portrays the experience of person-centred dementia care in the particular spatial and temporal contexts of each participant and the purpose of this analysis is to make sense of these portrayals through interpretation. This was an inductive process as the categories or dimensions of analysis emerged through the data. However, analysis was also an iterative and circular process as the data did not fit into 'neat and tidy' categories and required me to constantly reconsider and revisit the research materials as well as the literature in order to make sense of the data.

3.6 Methodological Limitations and Challenges

This section outlines the Methodological limitations occurring in firstly, the data collection stage and lastly, in the interpretation of the data.

3.6.1 Data Collection

The chief challenge arising in this project occurred during the data collection stage in the form of the difficulty with accessing resident participants. I received five responses from the primary healthcare representatives and only one agreed to meet with me. The others were either uncomfortable with their loved one participating in this type of study for fear of upsetting them, or they did not see the potential for meaningful communication between me and their loved one. This attitude represents old cultural perceptions of what it means to have dementia, adding to the stigma that already exists around the abilities of people with dementia, and effectively limiting their loved one's voice and views in their own representation. In this way, family members may narrow the world of their loved ones through their focus on protection and concern for them. This is discussed further in chapter 5.

Similarly, in hindsight, it would have greatly benefited this project if I had received ethics approval at the initial stages to include my field notes that were recorded during the volunteer work I undertook at TLAB. Utilizing this experience to familiarize myself with the environment and people in it enriched the project immensely and, especially in light of the fact that I couldn't gain access to more residents for interviews, resulted in much valuable information about resident's daily routines and relationships. Of course, this information though not used explicitly, is reflected in my interpretation of the interviews.

Findings were both enhanced and limited by my prior relationships with the participants. Such relationships made it difficult to be critical or evaluative as my positive view of the participants who I had met may have influenced how I viewed the data.

Furthermore, the staff and leadership who assisted me with my volunteer work were already positioned for me as experts and authorities on the subject which possibly affected how I viewed their responses, and how I prompted them throughout the interview.

3.6.2 Data Interpretation

Inherent in thematic analysis is the overuse or misuse of themes. By condensing the meanings of entire transcripts into workable categories, thematic analysis can strip away the nuances, complexity, and richness of the original expression (Luborsky, 1994). In this thesis, efforts to minimize this stripping were made by taking emotional reactions, contexts, and situational intricacies of the research encounters into account and recording such insights throughout the analysis process by keeping a paper trail. Additionally, my process of critical self-reflection throughout the study is thought to add a more nuanced understanding of the interpretations.

As a new and inexperienced researcher, I made the mistake of entering into the study with an *a priori* set of categories in my mind based on immersion in the literature. To my surprise, the interview data did not fit neatly into these pre-defined categories and at that point of uncertainty, I began the real business of qualitative research. I realized that it is not a linear process but an inductive, circular one always offering many paths to understanding, each one messy and meandering. In the end, categories and themes emerged from the data, and connections between these themes exposed themselves. It was only after this occurred that I could retrace the cognitive and practical steps I took to reach these understandings. The next chapter of the thesis presents the research findings.

Chapter 4. Research Findings

“Person-centred is a bit of a brand name, but what does it really look like?”
(A leadership member at TLAB)

The main goal of this chapter is to present the findings of the empirical investigation undertaken at Broadmead Lodge. The research began with two research objectives: the first objective being to better understand the roles of the physical and social aspects of the environment in the implementation of a person-centred philosophy of care through the experiences of the staff and leadership, the second being to represent the resident’s perspective of person-centred care in this environment. The subsequent chapter (5) will reflect on methodological challenges and barriers to understanding that were faced in order to inform future research with people living with dementia.

4.1 Leadership and Staff Perspectives

To address the first objective, the findings are arranged into three main sections: 1) physical aspects of the environment 2) social aspects of the environment, and 3) challenges to the implementation of person-centered care. As the stated goal of person-centred care (to maintain and enhance personhood) exists in the psychological dimension of the environment, the analysis looks at how the physical and social aspects contribute to this psychological goal. In these first two sections the physical and social dimensions are each further divided into three themes that were identified by the research participants: *identity maintenance, facilitating relationships, and aligning values*. These themes represent the most important theoretical links between the physical and social aspects of the environment, and the ultimate goal of maintenance and enhancement of personhood.

Discussion of the themes is followed by a consideration of their corresponding practical applications, notably, the specific ways in which the roles are played out. Moving from the general function of each layer of the environment (social and physical) to the more specific ways of carrying out those roles, and finishing with the challenges that were expressed by the participants, this section describes the lived experience of how TLAB has shifted person-centred care from the philosophy of dementia care to the practice of dementia care.

4.1.1 Physical Aspects of the Environment

Although the built environment was not a main component of Kitwood's (1997) or Brooker's (2004) initial formulation of person-centred care, interview participants invariably cited it as playing a crucial role in shaping experience. Many participants noted that the physical environment is especially important for the resident population at TLAB because of their high levels of impairment and complex care needs. Moreover, on top of their responses to the question about the physical environment, many staff and leaders included comments about or reflections on the built environment in their subjective understandings of a person centered approach to care. Notably, there is little to no mention of the physical environment with respect to its support in aligning values. Although this is supported through posting the mission statement throughout TLAB, it was not mentioned in the interviews and did not seem to be as important based on the interviews.

4.1.1.1 Maintenance of Identity/Comfort

“In a hospital, the space reminds you that your role is of a patient. In a school, it tells you your role is of a student. It’s amazing what happens when you let people

define space for themselves.”
(A Leadership member)

This quote alludes to the idea that the physical environment is not simply a passive entity within which people go about their lives. Rather, through a process of undermining or confirming expected roles, the physical environment plays an integral part in the maintenance of identity. This was identified by many participants as one of the key roles played by the physical environment in enacting person centered care. The staff and leadership at TLAB work within the fixed parameters of an institutional, communal arrangement, but aim to give individual residents a chance to remember and define their own identity through the physical space of the TLAB environment.

This is accomplished in several ways: by making sure that residents have as many personal belongings in their room as possible, by labelling the rooms with the residents' preferred name, and by adding ‘memory boxes’ at the door of each room to commemorate one or more accomplishments or interests of the resident. Physical artifacts in the residents' rooms such as pictures and furniture from their past lives further serve as reference points for the identity of the residents and remind them that the space is their own. As one member of the leadership team notes, “this isn’t their home, we know that, but we strive to make it as homelike as possible with a familiar environment to make sure that they have reference points.” Maintaining some of their personal belongings gives them ownership over at least a piece of the environment they live in.

As well as reminding the residents of their own identity, many participants added that personal artifacts and memory boxes allow the staff and leadership to have a quick access point to important aspects of their histories. Having other people recognize their

individual histories and relate to their personal artifacts further affirms the resident's identity and personality outside of the disease state. Recognizing that the resident's experience many changes when they come into the facility, the staff and leadership are flexible with respect to what the residents are allowed to bring in. Individualized rooms and personal artefacts help to maintain a resident's identity as well as remind them of who they are in spite of all the losses that come with being placed in a residential care facility. This is encapsulated in the statement made by a leadership member that, "having artifacts that they can hold on to in the event of agitation and knowing that the staff can use such artifacts to de-escalate that agitation by talking about something they are familiar with supports residents well-being." Getting to know and being supportive of the residents' emotional and sensory selves supports embodiment and is an important aspect of identity maintenance at TLAB.

As well as its capacity to maintain or undermine identity, many leadership and staff members noted that, "the built environment itself is a huge potential trigger for agitated behaviour" (Leadership member). Specifically, participants noted that the basic layout and physical features of the Lodge such as lighting, odour, and sounds can affect the residents physically and psychologically in a way that may result in adverse reactions. Conversely, the built environment can also be a source of comfort for the residents (both psychologically and physically) requiring the leadership and staff to consider every element of the built environment and how the residents might relate and react to these elements.

Many participants mentioned not only the visible aspects of the environment such as lighting and furniture, but also the smells, and especially the sounds as having a huge

impact on resident comfort or agitation. In general, the complex role of the physical environment is captured by one leadership team member who noted, “people with dementia get along much better in an environment with less people and less noise.” To address this concern, the smaller lodges that were renovated as part of the DCP offer individual rooms with outdoor lighting (windows) and access to a communal garden. Staff and leadership all agree that having fewer people reduces the noise and traffic and creates a warm and calm place or space that supports residents' well-being.

The garden in the courtyard was often cited by staff as an important source of comfort for residents. Even if the interaction involves touching the dirt or simply having it there to look at, it is viewed as an important element of the built environment. The role it plays is both as a visual and olfactory stimulant as well as an activity that can provide much comfort to residents, especially those who had been gardeners in the past.

To reduce agitation and exit seeking behaviours, murals were painted on the exit doors, one of which resembles a book case and the other, an image of a farm. These were a point of contention among the staff and leadership participants with some viewing them as important measures taken to reduce agitation for residents who may be tempted to exit, while others viewed them as superfluous because of the mandatory exit sign that sits on top of the door. At the very least, these murals were seen as talking points, employed to deter the agitated resident, and more visually pleasing than a blank door.

The decor and furniture in the common living area and kitchen are said to create a home-like ambiance that reduces agitation. As one participant noted, “There's a lot of thought that goes into the selection of not just the floor plan, but the furnishings as well.” There are a few reasons for this that were often mentioned by staff and leadership. The

first is to allow for mobility of residents in these areas, especially non-ambulant ones. The kitchen and common area must have sufficient space for residents in wheelchairs to move freely. Tables on wheels and with proper elevation also allow for comfortable navigation of the kitchen and common area. Second, as a result of the incontinence of some residents with advanced cognitive impairments, the fabrics allow for easy cleanup by the staff, thus reducing agitation for both staff and residents in the event of an accident. Third, the specific fabrics used are said to help absorb excess noise mainly coming from the kitchen which can cause agitation. Fourth, the staff is not expected to wear standardized uniforms which can contribute to an institutional feel. Instead many staff members wear street clothes that do not resemble institutional uniforms and therefore, convey to the residents that they are in a relaxed environment. And finally, the colors that are used throughout the space contribute to the overall experience of that space. Colors can either be a calming agent or cause confusion and agitation for the residents, especially those with advanced cognitive impairments who are especially sensitive to visual stimulants. These design considerations were made to combat the intrinsically institutional feel of communal living arrangements such as this one. Although the residents may not view TLAB as their home, the physical environment is created and manipulated to ensure them that neither do they feel they are in a hospital which gives them greater comfort.

4.1.1.2 Facilitating Relationships

“In a smaller environment it's a lot easier for staff and family to connect. These relationships allow for flexibility which is a key component of an environment that supports person-centered care” (Leadership member)

Many participants mentioned that flexibility is an important aspect of person-centered care and noted how forming relationships between staff, family, and residents allows flexibility to develop. By flexibility, the participating staff means the ability to focus on the care needs of individual residents over any rigid schedule for care tasks. The main idea is that in order to be aware of the resident's care needs, staff must aim to have a relationship with them, and if, for example, a resident's bed is not made, then the staff needs to be able to explain why to the family in order to maintain a trusting relationship. At TLAB they have found that the smaller lodges assist with a clearer understanding of the nature of these relationships.

For the residents, a smaller area with fewer inhabitants is said to give the staff a chance to form more meaningful relationships. This occurs through the staff getting to know the residents' preferred names, eating habits/dietary requirements, bed time and wake up time, hobbies, histories, and interests, in an effort to support their identity and well-being through acknowledging their individual preferences. It comes as no surprise that smaller and less institutional environments are believed to be better in providing more opportunities for interaction, gaining knowledge about the residents through their memory boxes and other memorabilia, and thus fostering relationship building.

For families, it is much easier to access the staff with any questions they might have about why a care task was or was not completed in a smaller environment. According to the staff and leadership, this also lends itself to a greater chance of interaction and communication that will ultimately lead to more information about the resident and consequently more flexibility in care tasks for the staff. A larger space with

more residents would make it more difficult for staff to remember the families and vice versa, as well as limit their interactions and chances for communication.

4.1.2 Social Aspects of the Environment

Social aspects of the environment include the values and expectations within TLAB. These were often cited as playing a major role in the implementation of person-centered care in support of the physical aspects. There is considerable overlap between the functions of these aspects of the environment. In essence, they are separated artificially here based on responses to questions explicitly pertaining to one or the other, while in reality they emerge simultaneously to shape the lived experience. This separation is helpful to magnify the occurrences of conflict, where one aspect may be hindering the overall goal of person-centred care while the other supports it. For example, if economic constraints don't allow for an ideal physical environment, a facility can focus on social aspects of care to make up for the physical conditions. Specific challenges in the implementation of person-centred care faced by TLAB are listed in section 4.2. Furthermore, this separation, though artificial, is important for this study to make sense of the data through the lens of human geography that views the environment as complex and multi-layered.

4.1.2.1 Maintenance of Identity/Comfort

“Yes, their history is important but also who they are now is important. The odd time I ask a resident, ‘how old are you?’ and they will say 20 or 17 which is a good reminder to always think about the environment in their context.” (Staff member)

Given that personal identities are understood within TLAB as being dynamic regardless of people's cognitive abilities, it is important to not only display the aforementioned reminders in the physical environment, but also to affirm and acknowledge the unstable nature of individual identities through the social environment. This is said to take place in TLAB through the person-centred language and communication approaches used when interacting with residents as well as through helping residents make their own care choices. Care is said to be provided *with* the residents as opposed to *for* the residents in a more clinical approach. As one leadership participant noted, "We try not to do to people."

Communication approaches with the residents used in TLAB can be summed up in this quote from a leadership member who tells us that, "Dementia care is a lot like doing improvisational theatre, you just go with the flow." The idea of 'going with the flow' was brought up by many of the staff and leadership who saw this as the best approach to communication that allows for the residents' version of reality to be affirmed rather than contradicted. This approach is in contrast to forcing your reality on the residents or forcing conversational conventions on your interactions with them which tends to undermine their personhood by questioning their world-view. Instead, staff and leadership talk about successful communication with residents with advanced dementia as a 'dance,' or 'improvisational theatre' where going with the flow by using phrases such as "tell me about it," rather than forcing your world-view on them can act to support resident identity.

Along with communication techniques, staff and leadership agree that the specific language used can act to affirm or undermine the personhood and identity of the

residents. This is exemplified by a member of the leadership who noted, "if you label people you tend to think about them as an object and forget about the individual behind it." Staff and leadership are expected to know the preferred name of the residents and to refer to them by that name rather than by a pet name such as 'sweety' or 'darling' or 'mama', or label them based on their care needs or clinical diagnosis (a common practice in many care facilities). Some more examples of person-centred language include: the residents are staying in a 'lodge' rather than in a 'ward' or 'wing' and residents 'move in' rather than being 'admitted'.

Another way that the participants noted the social aspect of the environment can affirm a resident's identity and world-view is the previously stated view of staff and leadership that they are caring with rather than for the residents. This is the idea of promoting choice and helping the residents make their own choices by spending the time getting to know what type of help they need. For example, a direct care staff member told me, "we have guys who love to sweep the floor and instead of banning them from doing so we bought brooms for them to use." The support for this flexibility in resident routines from leadership is shown in this quote from a leadership member: "people that have dementia have the right to say no as a semblance of having control. We don't make anybody do anything they don't want to do." In order to reconcile this flexibility in daily routines with the need to complete care tasks, staff and leadership cited documentation as being extremely important to make sure that everyone knows why a task wasn't completed and when the best time might be for that particular resident.

4.1.2.2 Facilitating Relationships

“Its not the amount of time you have, its how you spend the time. Every moment matters is really a shift in mindset where all of the time spent together is potentially an opportunity to have a meaningful moment” (Leadership member)

Here we are introduced to the phrase 'every moment matters,' a phrase that was said at some point in every interview with a leadership participant and many of the staff members as well. While the smaller physical aspect of the environment allows for greater interaction, the social aspect of the environment determines the quality of those interactions. Indeed, “sometimes just doing nothing and just being with somebody is enough” (direct care staff member). The ability to make every moment matter and thus, to form meaningful relationships in spite of the possible lack of down time with residents was said to require a shift in mindset from the perceived requirement of a large quantity of time with residents, to a commitment to the quality of time spent with residents.

4.1.2.3 Aligning Values

“ You can tell [leadership] is philosophically and morally completely on board with person-centred care. It's not just a job to them, they actually exude a deep commitment to it and that's inspiring” (A staff member)

The alignment of values throughout TLAB in the leadership and staff roles is seen as an important contributor to the creation of a person-centred environment. The physical environment can help to spread person-centred values; however, just as important is that the leadership embody these values. As a result, this is a goal that is largely accomplished by the leadership through their support of staff and is exemplified through education, modelling expected behaviours and treating staff in a person-centred manner.

One leadership member noted, “one of the ways leadership can support person-centred care between staff and residents is if we are person-centred with the staff.” This includes knowing staff members personally, being responsive if they need assistance, being cautious when providing feedback, and speaking to staff directly. Moreover, many staff members also noted that they feel they have a voice that can contribute to the environment in a meaningful way and that these conditions are set up by the leadership. Additionally, an “organizational wide buy-in” is said to be shown not only through providing education and supportive studies such as this one, but mainly through covering the staff’s shift while they go through the training or participate in research. As flexibility is expected to be allowed for the residents daily routines, it is also supported by leadership with respect to the staff’s daily routines as exemplified by a leadership participant who said, “we recognize that certain things need to be done within a certain period of time, but we also recognize if something wasn’t done the reason behind it was meeting the personal needs of the resident--that’s the more important thing. The bed can be made at any time.” And, notations can be captured in the documentation of staff which is recorded in a database on each Lodge after each shift. As well, regular meetings occur between the staff and leadership that allow this type of information to be exchanged.

Role modelling expected behaviours within TLAB is predominantly accomplished through the language used by leadership when describing or interacting with the residents. As one leadership member revealed, “if we don’t focus on using person-centred language then what happens is that it waters down all our other principles.”

The “Supportive Pathways” and “Dementia Difference” educational workshops were said to be extremely helpful for developing the understanding and pervasiveness of person-centred values. Although not everyone had the same level of understanding of the individual concepts, these two-day workshops provided the staff with at least a basic understanding of the philosophy and value base, a practical method and understanding of person-centred care, and showed a facility-wide buy-in by including all staff members.

4.2 Challenges to the Implementation of Person-Centered Care

In this section the following table consolidates the main challenges that the staff and leadership at TLAB perceived to be hindering the implementation of person-centred care. Not all of them were explicitly stated; however, they were all derived from my interpretation of the interview transcripts and are backed up by related quotations. These challenges will be addressed in greater depth in chapter 6 where I discuss the implications of this research and possibilities for further inquiry.

Table 4.1. Challenges to the implementation of person-centred care

Challenge	Explanation	Quote	Physical/Social Aspect?
Complete buy-in from staff	Leadership and staff noted that some staff members may not have bought in to the goals of person-centred care as they have been trained and are experienced in acute care settings. This causes a trickle-down effect where new staff may be affected by the more experienced staff's	“Some staff are still old-school. They want it their way or the highway. Some have been trained in acute care so that is still in their mindset” (Staff member)	Social

	attitude.		
Inherent difficulties with communal living arrangement	Ultimately this is a facility that contains a large group of people who all may have historically lived in a much different situation. It is always troublesome to create a prosthetic environment to try and please everybody.	“There's certain things in a big institution like this, meal times, laundry services, etc, that have to happen. People will always have trouble living communally.” (Leadership member)	Physical
Flexibility vs Efficiency	Certain tasks still need to be done in order to maintain an adequate standard of living. There needs to be a balance between flexibility of routines and efficiency of completing required tasks which is said to be a difficult one sometimes.	“When you introduce that degree of flexibility to the staff routine's you always lose something in terms of efficiency” (Leadership member)	Social
Lack of resources	While recognizing that staff members and leadership do the best they can at making every moment matter, many participants noted a shortage in staff members in many areas throughout TLAB. This is largely an issue of funding, but also makes quality time that much more important.	“staffing numbers are an issue, staffing will always be an issue” (Leadership member)	Physical
Continuity of staff	This was seen as an important aspect of forming relationships	“You sometimes end up with different staff every day so they	Social

	with residents as well as a challenging aspect due to staff turn around and union requirements.	don't know the resident. It's hard when people don't really know the person" (Staff member)	
Balancing personal values, family values, society's values	People have their own sets of values that may not always align with what the residents need. This was seen as the major challenge to the implementation of person-centred care.	"Humans always look for the path of least resistance. It's difficult to put aside: personal values of the people working with the residents, values of the family members that may not mesh with how the resident is now, and societal values that affect legislation in an effort to respect the resident's individual values" (Leadership member)	Social
Increasingly changing resident and family population	While the eligibility bar is raised for access to residential care and the population ages, residential care environments need to reflect the increased complexity of care needs. Also, as resident spouses get older and pass away, a new generation of family members with different expectations will need to be accounted for.	"The original built environment fit the resident population at the time, but now the people are closer to the end of their life, clinically complex and fragile and there's a higher level of cognitive impairment so it needs to change"	Physical
Documentation	Although documentation between staff and leadership was stated as being very	"It's hard to effectively communicate with the rest of staff as there is not enough	Physical

	important in the implementation of flexible routines for the staff and thus for the residents, it seems to be still a work in progress as the infrastructure may not be in place such as more computers on each lodge.	time to document and only one computer on each lodge” (Staff member)	
Difficulty putting yourself in the place of residents	None of the interview participants were comfortable with the last question asking what they might have changed if they lived as a resident at TLAB. This seems to echo the reluctance of society in general to put themselves in the place of people who are older and who have dementia and is the main reason why the resident perspective is so important.	In response to this question, a leadership member said, “I find that a really difficult question to answer.” This was a common response.	Social/Psychological

Of great interest to me is the challenge of “putting yourself in the place of the residents,” which arose from the responses of staff and leadership to the final question that asked what their likes and dislikes of the environment at TLAB would be and subsequently what they would have changed if they were a resident. The difficulty they had answering this question speaks to the inherent difficulty of trying to view the world from someone else’s perspective, especially when that means facing your own mortality as is the case with older adults with dementia. I view this difficulty as one of the main barriers to the implementation of person-centred dementia care from a policy perspective

as it amounts to a disconnect between individual values and society-wide resource allocations through policy initiatives. As stated earlier, there will be more on this in the concluding chapter.

4.3 Resident Perspective

For the second objective of capturing the resident's perspectives on an environment informed by person-centred care, the findings are expressed through a single narrative based on the one interview conducted with Jane, a resident in Palm North Lodge. As stated in chapter 3, this interview took the form of an informal conversation and, as such, I employed a different analysis technique than the semi-structured interviews with the other participant groups. This section is largely made up of quotations from Jane that I believed to be meaningful based on my knowledge of the resident. The quotations are followed by stories and explanations behind them. This provides a glimpse into one resident's lived experience of an environment informed by person-centred care and ultimately helps give the resident a voice in her representation.

This section is as much a methodological exploration as it is a portrayal of my findings. It shows that communication and research with people that have advanced dementia is possible, albeit difficult, with some background information about the individual and the ability to be epistemologically flexible and open-minded throughout the communication process. Although I have not reported any direct observations from my volunteer work, much of what I know about Jane was gleaned through my relationship that developed when I was in the role of a volunteer. As a result I cannot help but apply this information to my understanding and interpretation of these findings.

Furthermore, as considered in the discussion of reflexivity in chapter 3, my interpretation of Jane's responses and behaviour is filtered through a philosophical lens/orientation that is made up of not only my experience at TLAB and Jane herself, but also my academic and historical background.

With that in mind, what follows is the story of my meeting with Jane and her daughter, Linda with a bent towards meeting the research goal of gleaning a residents' perspective of an environment informed by person-centred care.

I met with Jane's daughter, Linda in the TLAB foyer where we signed in as guests and headed to the Palm North Lodge for the interview. We arranged to meet at this time because it is typically when she visits with her mother and we decided that it was important not to disrupt Jane's daily routine in any way that was not necessary. As noted in chapter 3, Linda would be present for the interview, and at this point I was not sure whether or not that would be helpful. However, it did not take long for me to realize how important her presence and perspective would prove to be. The perspective of family members was not taken into account in this research due to time and resource constrictions. However, chapter 5 will discuss how this missing perspective may have enriched this project and why I believe that future research endeavours should include this group as an important aspect of the experience of long term care.

We took the short elevator ride down to Palm North where we were greeted by some staff members who were extremely supportive of the interview process and our presence in the lodge, as always. The fourteen residents on Palm North were spread out throughout the lodge but we had no problem finding Jane who was socializing with a fellow female resident, Helena, who had become her friend since she moved in. They

were walking up and down the main hallway together exchanging the occasional laugh and, though Helena speaks no English, seemed to be exchanging meaningful information. Whispers were followed by mischievous facial expressions that appeared to affirm the opinions they each had about the other residents' behaviours, how they kept their room, the physical environment including paintings and memory boxes, and pretty much anyone in the Lodge who paid them any attention. They were conversing as two friends might do. However, their judgements and observations were expressed through facial expressions and tone of voice rather than words. Helena, who speaks no English and spends most of her days walking between the two ends of the Lodge, was clearly enjoying the company of Jane, who is typically more of a social butterfly. I think to myself, "if these two women can understand each other and communicate effectively, both experiencing advanced cognitive impairments, what makes it so difficult for me, a self-proclaimed rational and cognitively intact individual to interpret their actions?" Clearly, there is more to communication than words alone, and having put words on a pedestal for so long, I often overlook the other complex embodied relations from which meanings emerge. This has nothing to do with the residents' ability to express themselves, and everything to do with my inability to recognize and interpret meaningful expressions. More detail on these types of challenges and the epistemological implications are presented in chapter 5.

Not wanting to be too invasive and noticing that the two were enjoying themselves, Linda and I joined Jane and Helena for a walk, during which I encountered a few other residents who I met as a volunteer. They were curious as always to see me back in the Lodge.

One of these residents, George, who I had always felt a strong connection with acknowledged my presence as he always did, by stroking his hair in a way that was imitating/mock my comparatively long and stylized locks. This was followed by a ‘thumbs up’ which I returned, and an extended handshake that we maintained throughout the conversation that ensued. I have always interpreted the ‘thumbs-up’ as an acknowledgment that I had been a good sport about George’s teasing and a test for him to see if we were connecting on some level. The first few times we met I did not respond in a way that told George I would acknowledge him in the way that he would like and he proceeded to signal me away with a stroke of the hand. This time I was accepting of his worldview and communicative approach, signaled by my returned gestures, allowing the interaction to continue in a way that was meaningful for both of us. George and I then embarked on a communicative process that included rationally incoherent sentences, acknowledged by responses that were understood through the tone of voice and body language which I viewed as similar to those of the interactions I have with my own grandpa. He seemed to recognize that I was younger and as such, was imparting wisdom along with a touch of playful sarcasm. I was able to recognize all of this by spending time with George that allowed me to thoughtfully consider our interactions, and his reactions to different tones of voice and interpretations of his behaviour. When I stopped trying to understand his words, and began to be sensitive to other expressions of meaning, I felt I was able to enter his worldview and gain confidence in the interaction.

Through this relationship I learned that successful communication takes time and patience. As well, I learned that communication is not always in the form of words, and for successful communication to take place I am required to be open to a social world that

is not necessarily focused on words but can still be full of meaning (Kontos, 2005). This is an incredibly difficult lesson to put into practice. Especially for someone like me who in theory can appreciate, and is sensitive to a broad interpretive lens, but often tends to place a heavy weight on rationality and words on an epistemological pedestal. Chapter 5 includes further discussion on this point.

After a visit with some of the staff members, I asked Jane if she would like to sit down with me and Linda for a chat about her experiences there, and she looked puzzled so I followed by asking if she cared to sit down with me and Linda for a hot chocolate. This was something Jane was interested in and we subsequently escorted her to the kitchen to formally begin our visit over three hot chocolates that were graciously prepared by a care aid.

“Funny how you get together and all the memories come flowing right back”

The first half of the conversation was largely guided by Jane and Linda. They reminisced about Jane’s history, growing up in England, meeting and being courted by her late husband, and relayed many incredible experiences they had as a family that they were able to share with me and each other. I was delighted to hear Jane speak so vividly about her past and how she provided some very specific details that I felt anyone would have trouble remembering. Jane told us that she was banned by her mother from interacting with the soldiers who were stationed in a field behind her house in a small English town. She went on to explain how she had tiptoed around that rule by taking the dog for a walk and simply allowing him to lead her to the field. This way, she could fulfill her curiosity about the soldiers while keeping her mother at bay. On one of these occasions Jane happened upon her future husband and “the rest is history”. Her daughter

seemed to trigger this flow of memories by acknowledging Jane's versions and instilling confidence in her story thread by nodding and maintaining eye contact which seemed affirming. Jane has not lost this cheeky demeanour. This was apparent when she summoned Linda to her ear and asked with a mischievous expression and tone, "where did you pick this one up?" referring to me. Linda told her that we met out front and that I am here to talk about her experiences here and Jane concluded the interaction with sort of a wink implying that she is on to us. Jane has often reminded me while we peruse magazines and drink hot chocolate together that, although she is happy to spend time with me, that she must tell her husband and he may not be happy. I ask her to tell me about her husband and tell her that I would love to meet him, and we carry on.

Jane's experience of the world seems to be largely based on long-term memories. While she can vividly describe the home and town that she grew up in as well as many specific experiences she had there, her short-term and present understandings are quickly diminished. This is exemplified by her changing perception of me throughout the interview as she would intermittently ask who I was or where/when Linda picked me up and was often visibly confused by my presence. As a result, knowledge of Jane's past is integral in making her communication attempts meaningful as they need to be placed in their historical context and are often explicitly referring to projections of her past on the present situation.

Jane was very comfortable throughout the conversation, as expressed through her body language and confident speech, until she saw or heard other residents that she had a history of conflict with. She told us that residents occasionally entered her room and that we need to look out for them. This is an obvious difficulty of living communally.

However, she also would smile as her friends would walk by and even exchanged words with her friend from earlier who we invited to sit with us but she decided to keep walking. The relationship between residents is clearly an important one to keep in mind when considering the residential care environment. When I asked about who her friends were in Palm North, she lamented, “love[em] and leave[em] friends here.” This was surprising to me as I know her to be extremely outwardly social with all of the staff members and many residents, and expected this to be a positive aspect of the environment for her.

Social relationships were a major factor in Jane’s wellbeing throughout the interview. Her mood and clarity changed drastically depending on who she was speaking with. Only as I began to feel comfortable in the conversation did Jane begin to speak to me directly rather than through her daughter. It was then that I asked her, “what do you like about living here?” and she responded with:

“I’m seriously thinking about moving out”

Although this statement seems entirely negative, it shows that she feels she has a choice in the matter. As a result of how she is treated in TLAB, Jane often speaks about it as if it is her home. She mentioned that she had to check on her children or her dog, “upstairs” which seemed to mean in her room and no one would tell her otherwise. Instead a discussion of her children or dogs (she is a dog lover as exemplified by the many photos in her room) would begin and she would again feel at ease. She does not particularly like the food as expressed by the comment, “we get baby food in here,” however, she expressed that she was happy to not have to worry about making dinner every night.

At this point an activity staff member approached us with a cart of arts and crafts. She showed Jane an example of what they were making upstairs and asked if she might like to make some later on. We all agreed that this was a good opportunity and that she should come back later to escort the resident to this activity. Instead of forcing the residents into large group activities that are mandatory, the activity staff makes sure that individual residents could benefit, or not, from the activity based on prior knowledge of the resident as well as present reactions to the offer. This gives the resident a choice in their daily routines thus affirming their identity.

The physical environment did not get as much direct attention as social relationships in this conversation. However, she mentioned her appreciation of the garden as it reminds her of where she grew up. She does not watch much television but spends much of her time in the common living room where people tend to congregate, and walking up and down the hallway with her friend. As mentioned earlier, she has had some issues with other residents entering her room unannounced, but the freedom of movement seems to override that threat. The main role of the physical environment for Jane seems to be fostering relationships with residents and staff. The freedom of mobility allows her to make use of many artifacts that help facilitate social interactions (paintings, books, etc) and allows her to remove herself from unwanted interactions (room intruders).

After two hot chocolates and a few wafer cookies, our hour had passed and Jane was showing signs of fatigue so we decided to end the interview.

4.3.1 Summary of Insights

This interview gleaned a number of key insights about the lived experience of residents in residential care. Although it gets little attention in the literature, the relationship between residents is an important one to foster. Jane's daily experience is largely shaped by these relationships as the freedom of mobility and flexibility of daily routines allowed in Palm North amounts to large amounts of interaction between residents. These can be positive such as Jane's friend who she enjoys walking and gossiping with, or negative such as finding an unwanted guest in her room. Recognizing and supporting the positive interactions through the physical and social environment is essential to enhancing the quality of care and quality of life for the residents.

Recognizing the diminishment of short-term memory, long-term memories need to be fostered through physical reminders and strong social ties. In Jane's case, family members play an important role as Linda's shared memories triggered a flow of memories in Jane that provided her with comfort and confidence. In contrast, Jane's short-term memories such as how she viewed me were dynamic and hazy causing some agitation when asked about them or when she attempted to communicate about the present circumstances.

Communication with people with dementia often takes place outside of conventional understandings of how a conversation should proceed. Jane had little interest in responding directly to the research questions such as 'where is your favorite area in here' and 'what do you like to do here,' as they require the access to relatively short-term memories and are far too specific. These types of questions only served to

agitate Jane and seemed to undermine her versions of reality by expecting her to enter mine.

This process, while providing a small glimpse into the everyday lives of people with dementia, has taught me methodological and personal lessons that can assist other researchers to include people with dementia in a meaningful way and ultimately give them a stronger voice in their representation, notably meeting them where they are, historically and literally, and also being keenly aware of their non-verbal communication.

4.4 Summary of Findings

For the first objective of understanding staff and leadership perspectives on how person-centred care is operationalized, the physical and social aspects of the environment were both viewed as playing major roles. The physical aspect of the environment helps to maintain resident identity and comfort through including personal artifacts as reminders and providing a home-like surrounding that is said to reduce agitation. The smaller environments created as part of the DCP facilitate relationships by increasing interaction between families, residents, staff and leadership. To help align values within TLAB, gentle reminders are located throughout the facility in the form of posters to help staff and leadership understand and remember the mission statement as well as some tips on how to accomplish this. The social aspect of the environment contributes to the maintenance of identity through communication techniques, specific language used, and caring with rather than for residents. Meaningful relationships are facilitated through application of, and attention to the expression, “every moment matters,” that emphasizes the quality of time spent with a resident over quantity. The values of person-centred care

are aligned through the leadership: providing educational workshops, role modelling of expected behaviours, and treating the staff in a person-centred manner.

Challenges to this operationalization come from both the physical and social aspects of the environment as well. The physical challenges are documentation technology, changing resident populations that require more support, lack of staff and other resources, and the inherent difficulties with communal living arrangements.

Challenges posed regarding the social aspects of the environment include getting a complete buy-in from staff, flexibility of routines versus efficiency of completing tasks, balancing values, and the difficulty putting yourself into the place of residents.

The resident interview provided only a small glimpse into the experiences of residents in an environment informed by person-centred care. Of greatest importance were the relationships that the resident had with me, the staff members and her family member that greatly affected her comfort level and ability to express herself. Methodologically, it is apparent that in order for any meaningful information to be exchanged, researchers need to develop a prior relationship with the person with dementia. Although the residents didn't always remember the specifics of who I was (i.e., Jane's changing perspectives of me throughout the interview), having a prior relationship made me better equipped to understand and navigate these changing perspectives.

Chapter 5. Discussion

The previous section describes the implementation of person-centred care at TLAB and offers an interpretation of my interaction with Jane, a resident, to satisfy the first and second research goals, respectively. While the process of addressing the first research goal was fairly straightforward and descriptive, the research process for the second objective unearthed a gamut of methodological and epistemological challenges. These challenges are worthy of discussion in an effort to inform future research endeavours involving people living with dementia. They effectively limited my understanding of the lived experience of the residents and thus could contribute to a misrepresentation or under representation of the resident's perspective. To this end, I am directed in this chapter, as Malcolm Goldsmith (2002) was, to consider not only the content of the interview with Jane, but also the process and my own reaction to it, or as Goldsmith puts it, to explore "To what extent were some of the problems of communication my own problems rather than the problems of the person with dementia, and to what extent did the very process and the 'mindset' that I brought have an effect upon the communicative relationship?" (p. 19). As well as reflecting on issues of communication, I endeavour to account for the myriad of institutional and methodological difficulties that were faced that may have hindered my ability to access and interpret 'the resident' perspective. By placing the problems of communication on the shoulders of the researcher rather than the person with dementia, this can be viewed as contributing to a person-centred approach to qualitative research that affirms the continuing abilities and uniqueness of the person with dementia.

This chapter is divided into two sections: personal challenges and methodological barriers, each representing an aspect of the research process and containing specific epistemological and methodological difficulties encountered or research errors in that aspect. Some of these difficulties are engrained in the institutions and academic framework involved in scholarly research, while others stem from my own limitations and mistakes that were discovered after reflection.

5.1 Methodological Barriers and Limitations

Although much thought and planning went into developing the methodology for this project, upon further reflection there were some choices and barriers that limited both the access to residents and the quality of the information gathered. As the practice of doing research with people living with dementia remains an exploratory one, it is important to render these errors and difficulties explicit in an effort to contribute to future research with this group.

This section begins with a discussion of the missing pieces and perspectives that failed to be recognized early enough into the project and may have helped to shed more light on the experience of the residents. It then describes some specific research methods that were not employed and the various reasons they were left out of the project as well as some issues with the methods that were employed. Some of these gaps reflect institutional barriers while others were methodological choices. The influence of time and other resources on the research approach are laid out. Finally, the personal challenges that I brought to this project and may have affected understanding are brought to light. Included in each of these areas are recommendations for future projects that aim to capture and represent the voice of residents with dementia.

5.1.1 Missing Pieces and Perspectives

Upon further reflection, there were two substantive omissions in this study that would have greatly enhanced the amount of information gleaned to address the second research question regarding the lived experience of residents: family members and a lack of resident voices.

Of the fourteen residents living on Palm North Lodge, I was only able to access one (Jane) for the informal interview process. Initially I had hoped for three to five resident participants; however, the recruitment of residents proved to be a very difficult process with access to this population largely being restricted by family members.

Given the moderate to advanced level of impairment of the residents on Palm North, it was recommended (and eventually required by the ethics council at the Lodge and UVic) to gain consent to this group by proxy, as the residents were deemed unable to speak or give consent for themselves. I view this as an institutional manifestation of the clinical view of dementia that undermines the personhood of people living with it.

Although it is in place to ensure the safety of the residents, I think that it's imperative to get to know the individuals with dementia as a safeguard against agitation or risk. This way the decisions about who to involve in the research are based on situational capacity or present state of mind at the time of the research interaction and willingness to be involved, which are best understood after a relationship has been formed. That said, in this project consent was gained by proxy through the primary healthcare representatives of the residents. Therefore, my access to the residents hinged on their support rather than that of the residents' themselves. As noted in chapter three, the representatives (typically family members) had little interest in involving their loved one in this project.

The representatives who did respond to the recruitment attempts and did not want to be involved cited either that they would not be in the area to facilitate and that they would need to be there for an interview to take place (their presence was not required but it was promoted), or that an interview with the resident they represent would not yield meaningful results due to their perceptions of the level of cognitive decline of their family member. The former reason can be attributed to a concern for the resident's safety and wellbeing. This is an important consideration for such a vulnerable group; however, in this case I believe the benefits of being interviewed far outweigh the risks. Although this was stated in the recruitment letters there is still a lack of trust for outsiders as well as a perceived lack of ability of the residents to express and protect themselves. This is one of the major limitations of consent by proxy as it is difficult to describe the relationships that I had already formed with the residents through my volunteer work which would have allowed me to properly gauge the situational capacity of the residents so as to not cause any harm or agitation that the representatives were wary of. The latter reason seems to relate to the pervasive clinical perception of dementia and the people who live with it as being completely removed from the social environment and incapable of expressing their experiences of the world.

It is easy to forget, after engaging with so much literature on the culture shift and person-centred care, how pervasive the clinical view of incapacity continues to be. This view is another barrier for access and ultimately for understanding of the perspective of people living with dementia. That said, it is important here to be sensitive to the loved ones who have witnessed profound changes in behaviour and capacity that could easily be mistaken for a loss or change in personhood, whereas the researcher is presumably

coming from a relatively blank slate. To overcome this disconnect, not only is it necessary to get to know the resident, but also to get to know the family members in an effort to gain trust as well as information about the residents past that may not be available in the facility.

The one family member that I did meet with (Linda) proved to be an invaluable part of the research interview with Jane, as well as having many important insights and perspectives of her own. In general, I found that family members are an integral part of the care team and typically are involved in most of the care decisions. Furthermore, they bring a wealth of experience with the resident and knowledge of the resident's past that can help understand current behaviours and care needs. In this research the reasoning behind not including family members to begin with was based upon time constraints that are exacerbated by large amounts of data, as well as initially only wanting perspectives of people who either lived or worked in TLAB (residents, staff, management). The reality is that family members are very much involved in the lives of staff, management, and especially the residents and therefore have much to contribute to conceptualizations of the lived experience in TLAB. The involvement of family members is part of TLAB's Dementia Care Program, which was put in place to provide the guidelines for the implementation of person-centred care. In this program, family members are essential elements of the person-centred philosophy and its operationalization. Moreover, as stated earlier, I believe that if the family members were directly involved in the research process they would be more inclined to consent to resident participation, though consent by proxy remains an undesirable option (Dewing, 2002).

While the missing voice of family members was thought to be a practical and calculated omission, the lack of resident voices in this research remains mostly due to attitudes of family members and methodological choices.

5.1.2 Study Limitations

Several lessons were conveyed as a result of this research project. Conventional research methods such as semi-structured interviews that rely on carefully thought out interview guides are not the ideal approach when doing research with people living with dementia, especially for those in the moderate to advanced stages of the disease (Aggarwall, et al., 2003; Train, et al., 2005). This is due to the limited avenues for understanding (mostly oral) provided by interviews and the short span of time allowed for interaction (e.g., one hour to 90 minutes). Furthermore, scheduling interviews ahead of time did not allow for the flexibility required to ensure situational capacity of the person with dementia at the time of the research encounter. Although these issues were addressed in this project through the knowledge gained about the residents in my volunteer work, I still found the interview process to be somewhat invasive and limiting as far as the quality of the interaction. As a result I would recommend that a greater participant observation period be included along with interviews with family members.

For these reasons, more meaningful interactions seemed to take place during my volunteer work, as I held no preconceived notions about who to interact with or what information I was looking for. This allowed me to take my time getting to know the residents and to join in on their daily routines, rather than imposing a rigid research schedule on them. Although I kept a research journal that depicted this process, my

experiences with the residents, and my impressions of the resident's experiences, I did not request ethical clearance to include this information directly in this project. The initial reason for this was that I wanted to focus on my role as a volunteer rather than be distracted by other requirements. As well, I felt that spending time in TLAB with the residents would enhance my knowledge of the inter-workings of the research site as well as bolster my confidence and ability to communicate with people living with dementia. Therefore, I intended for the information gained to be used to inform who would be interviewed and my interpretation of the interview. With the help of the staff and other volunteers who were very supportive and taught me much about communication and relationships with people with dementia, I was successful on all of these fronts and the project was enriched as a result. However, what was ultimately missed out on is the information contained in the research journal which offers a more nuanced and meaningful picture of the lived experience of the residents than could be gathered through a relatively rigid interview process. In my case, I was unable to use this information as I did not have ethical clearance, however, in hindsight, a participant observation method I undertook in the form of a research journal recorded after volunteer shifts was helpful to allow for more voices to be heard, and I believe would it has the ability to produce a more vivid picture of the lived experience of residents. As this revelation did not occur until after the interview data were collected, I thought it would be best to move forward with what I already had based on time constraints as well as recommendations from my research partners at TLAB.

An additional method that may have been helpful to enrich the interviews is photovoice/photo elicitation (Wiersma, 2011). This method affords a collaborative

interview technique where the conversation is guided by photos of the environment taken by either the researcher or the subjects (auto photo elicitation). A benefit of the technique is that it gives people living with dementia another form of representation, communication and expression other than just their voices as well as allowing the researcher to focus on specific aspects of the environment that are conveyed in the photos. Initially I had hoped to make use of this technique as a way to access other avenues of meaning; however, it proved to be too time consuming and difficult with respect to consent as it would have required consent from the proxies of all residents on Palm North. Through my volunteer work, I found that communication with the residents was often facilitated through artifacts such as magazines, books, and pictures either in the main hallways or in their rooms. Without these artifacts to appeal to it was often difficult to sustain engagement and to find a common epistemological ground between myself and the residents. This was most apparent during the first few visits as at that point I had little knowledge of each individual resident. As a result many relationships were formed or facilitated through a common interest in, or at least a common acknowledgement of, things such as pictures, books, and magazines.

A common theme and recurring issue that affected the methodological choices and quality of information gained were the constraints of time and specifically the allocation of time as fleshed out below.

5.1.3 Time Constraints and Allocation of Time

“Communicating with a person with dementia can be a slow process. We must be prepared to devote an adequate and appropriate amount of time to this task...Not

having enough time, and therefore making little progress, is not the same as saying that the person is unable to communicate.” Goldsmith, 2002, p 76.

This quote from Malcolm Goldsmith illustrates the importance of spending ample time with people with dementia for successful communication to take place. In the context of this research project the time spent with residents was in the role of a volunteer and was to be used as a way to inform which residents would then be interviewed, as well as to develop my own perspective on the environment. In terms of lessons learned, much time was spent creating interview guides and recruitment materials that were ultimately unsuccessful for this group due to the need for flexibility in timing as well as understanding. In order to ground the analysis in the actuality of the residents' daily routines and experiences rather than according to my research schedule and themes included in the interview guide, I would have not only included the research journal observations (as noted in the last section), but focused my time and efforts on spending as much time as possible with the residents. This would allow me to reach more residents as well as increase my ability to communicate and interpret the information from residents.

5.1.4 Personal Challenges

Why study aging? To better understand ourselves (Mondale, 1988, p. 369)

Communicating with people with dementia provides an opportunity to reflect on personal challenges or shortcomings which may act as barriers to understanding. When communicating with a person with dementia, Kitwood (1993) recognized that rather than blaming the person with dementia for misunderstandings, the weight of difficulties in understanding should rest on the shoulders of the non-afflicted person. Until we reflect on this process and adjust accordingly, the interactions will remain superficial and

stereotypes of incapacity that justify mistreatment and malpractice could remain. As a young and inexperienced researcher with little experience communicating with people with dementia, I felt limited in the field during my volunteer work as well as the research interview. These shortcomings were reflected upon in my research journal after each volunteer shift as I attempted to overcome them and be a part of more meaningful interactions with the residents.

The first glaring issue was a reliance on language and rationality in the search for understanding. This is because people with dementia often make use of other means of communication to account for the decline in cognitive abilities such as face and hand gestures, and tone of voice (Kontos, 2005). In hindsight, by placing rationality on an epistemological pedestal, I feel that I missed out on communication attempts. In the field, I often became confused while the residents became agitated as they could feel that I was uncomfortable. Rather than attempting to match what is said to some conventional truth or a version of reality, it is helpful to let go of any preconceived notions about how a conversation should flow. This opens up a new pathway for understanding that allows for more a more meaningful interaction to take place that affirms the world-view and communication attempts of the person with dementia. As stated in the previous section, this process of letting go of conventional notions about how a conversation should proceed requires quality time spent with the person with dementia and is different for each individual.

Moreover, as Sabat (1991, 1999) and Gentry and Fisher (2008) describe, the behavior of conversational partners has a large impact on the verbal behavior of people with dementia, where Gentry and Fisher add that, “listeners in conversation can facilitate

the communicative process by modifying their verbal behavior" (p. 79). This arises out of the recognition that the verbal abilities of people with dementia tend to deteriorate as the disease progresses. Therefore, a verbal intervention should focus on the verbal behaviors of the conversation partner rather than trying to teach or change the speaker with dementia. One such intervention that is promoted by Sabat and others, called *indirect repairs*, consists of the listener providing additional descriptive information by restating or paraphrasing his or her understanding of the intended message of the speaker with dementia (Sabat, 1991). Gentry and Fisher note that, "indirect repairs can function to orientate speakers to the referent (i.e., topic of conversation) and may positively reinforce verbal behaviors" (p. 80).

As a new researcher, I failed to recognize early on how important the participant observation aspect was. Having little experience communicating with people with dementia, I naively believed that if asked the proper questions, the residents would respond with direct answers and the analysis would consist of coding for themes which were largely predetermined (though not explicitly). I did not foresee the difficulties associated with research with people with dementia, or the affect an experience like this would have on me. An important lesson learned from this experience is that doing qualitative research is as much a look inwards as a look outwards at the data, exposing your own shortcomings and biases. This is especially true with research involving people with dementia who in this case have significantly changed my own perceptions as much as, and possibly more than, I would illuminate theirs. Moreover, I was greatly affected by the relationships formed as a volunteer that connected me personally with the research, and taught me a great deal about myself. This personal connection certainly

affected the methodological decisions I made as I began to understand the feelings of concern and protection experienced by some of the family members who were approached for consent.

Chapter 6. Conclusion

This case study of The Lodge at Broadmead employed geographical concepts and frameworks along with qualitative methodological approaches and techniques to answer two main questions: How has TLAB implemented a philosophy of person-centred care in their residential care environment and secondly, how then is this environment experienced by a resident? Reflections on the methodological barriers and limitations for doing research with people with dementia enrich the project by providing some direction for future research with this group as well as exposing how the researcher and research process affected the quality of information and the ability to meaningfully interpret information from people with dementia. This chapter provides a summary of the research project followed by the implications of the study findings and the opportunities for further research brought to light by this inquiry.

6.1 Summary of the research project

Having aligned the fields of health geography, geographical gerontology, and dementia care through their shared conceptions of place, health and aging brought about by parallel paradigm shifts (the cultural turn and spatial turn for health geography and geographical gerontology and the culture shift in dementia care), this project employed theoretical frameworks from various branches of geography to provide a nuanced perspective of how human geographers might study the experience of dementia care. Members of the direct care staff and leadership at TLAB were interviewed in order to consider the layers of the environment as an influence on person-centred care in the implementation of the philosophy of person-centred care.

The singular interview with a resident at TLAB helped to situate and represent her perspective of the experience of this person-centred environment. Additionally, various methodological barriers that were encountered were discussed in an effort to reflect and find meaning in the research process itself, and help to inform further research with people with dementia.

The interviews with staff and leadership at TLAB revealed the ways in which the physical and social layers of the environment contribute to implementation of person-centred care from their perspective. These include the ways that staff and leadership work on the maintenance of identity, facilitating relationships and aligning values.

By including personal artifacts in each resident's room, the physical aspect of the environment at TLAB is revealed to help to maintain the identity of the residents in the face of cognitive decline. Rooms are labeled with the preferred names of residents and other facets that support identity include memory boxes at the door of each resident's room, and altering the layout of the environment to reduce excess noise, odors, and to limit the overall institutional feel of TLAB. Ongoing relationships between staff, residents, and family members are facilitated in the physical environment mainly through reducing the size of the purpose-built lodge for people with moderate to advanced cognitive impairments. Posting the mission statement and slogans such as "every moment matters" throughout TLAB acts to reinforce the values of person-centred care as a shared base for everyone in the facility.

The social aspect of the environment at TLAB helps to maintain the identity of the residents through the use of person-centred language and communication

approaches used when interacting with residents as well as through helping residents make their own care choices. In this sense, care is said to be done *with* rather than *on* the residents. Meaningful relationships are facilitated between residents and staff by returning time and again to the idea that ‘every moment matters.’ Encapsulated within this slogan is the shift in mindset for staff from being task oriented to treating all of the time spent with residents (even in a care task context) as a potential opportunity to have a meaningful connection with the residents. This supports the quality of relationships within TLAB, while the smaller size of the lodge increases the opportunities for interaction. The leadership at TLAB help to align the values of staff towards a facility wide buy-in to the tenants of person-centred care through the social environment by supporting staff through education, modelling expected behaviors, and treating the staff in a person-centred manner.

The interview with Jane, a resident at TLAB, resulted in a number of insights about the lived experience of a person living with dementia in a residential care facility. Firstly, although it gets little attention in the literature, the relationship between residents in residential care is an important one to foster. Recognizing and supporting the positive interactions through the physical and social environment is essential to enhancing the quality of care and quality of life for the residents. Secondly, recognizing the diminishment of short-term memory, long-term memories should be cultivated through physical reminders and strong social ties. In Jane’s case, family members play an important role. Her daughter Linda’s shared memories triggered a flow of memories in Jane that provided her with comfort and confidence during the course of our interview. Lastly, methodological and personal lessons were highlighted through this interview

process that can help to assist researchers to include people with dementia in a meaningful way and ultimately to give them a stronger voice in their own representation about how the environment in which they reside can better support their lived experience.

6.2 Overall implications

This section reflects on the implications that arise from this research project. It is separated into the methodological and policy-related lessons learned through the findings as well as the research process.

Family members are very much involved in the lives of staff, management, and especially the residents and therefore have much to contribute to conceptualizations of the lived experience in TLAB. Methodologically, involving family members and formalizing a participant observation method in the form of a research journal recorded after volunteer shifts ensures situational capacity, reduces invasiveness, would allow for more voices to be heard, and I believe would produce a more vivid picture of the lived experience of residents.

As stated earlier in the thesis, I believe that the benefits of interviewing residents far outweigh the risks. Theoretically, the necessity of obtaining consent by proxy undermines the capacity of individuals living with dementia to make decisions for themselves, thus reinforcing stereotypes of incapacitation. On a practical level, consent by proxy only serves to add another methodological barrier to representing the voice of individuals living with dementia. An alternative may be to add a requirement that the researcher has spent a certain amount of time with the resident as to allow for a better

understanding of their situational capacity. Furthermore, the presence of a family member or care aid who has an understanding of the resident's history and present capabilities can help to facilitate the research encounter.

It is critical for researchers and health care practitioners to understand that people living with dementia have a rich social world that is full of meaning, however this world can be overlooked due to the diminishing conversational abilities of those living with dementia. Further research with people with dementia should properly consist of much time spent with them in an effort to form meaningful relationships that help the researcher adjust to support individual continued capacities of the person with dementia.

Additionally, I have come to recognize that framing the philosophy of care at TLAB as one that is being 'operationalized,' or 'implemented,' is a superficial version of the situation. The reality is that person-centred care at TLAB is more than a way of doing care tasks. It is a fundamental, facility-wide, culture shift in ways of understanding and relating to the residents. This shift echoes a society-wide thrust in a similar direction towards humanizing conceptions of people living with dementia in general that results in the creation of environments that support this human aspect; this personhood.

6.3 Final thoughts and opportunities for further research

According to Sheila Peace (2006) Where you are both affects and reflects who you are. Environments do not exist in a vacuum. They are dynamic and thus are constantly created and recreated through a value-laden process and therefore can reveal much about the individuals and groups living in them. The complexity in this simple statement is magnified when considering environments for the most vulnerable groups

such as older adults and especially those with dementia. As Cohen notes, “the existence of catastrophically and chronically ill people compels us to discover what it means to be human” (Cohen, 1991, p. 11). Society should heed this message in the face of demographic aging trends and our ultimate fetishizing of youth cultures.

This project has focused, for the most part, on the nature of relationships between residents and staff/leadership at TLAB however, moving forward, the nature and range of relationships between staff and leadership in the care-giving context should also be examined further. On this point, I am perhaps most intrigued by my question to staff and leadership at TLAB who were asked to put themselves in the shoes of the resident’s and comment on what they might want to have changed if they were in TLAB in the capacity of a resident. The great difficulty they had with answering this question spoke volumes to me as to why this disconnect between individual values and resource allocation decisions exists and how much work there is left to do at the end of the day. Conducting mixed focus groups with these groups around this specific question and discussing the nature of relationships between them would be extremely meaningful.

As individuals and as a society, how we view and subsequently care for the most vulnerable can tell us much about ourselves. As Pat Armstrong, a prominent health researcher in the field of long-term care, tells us, “How we treat this vulnerable population and those who provide their care is a critical indicator of our approach to equity and social justice, as well as to care. Long-term residential care is a barometer of cultural values and practices” (McLean, 2010). This information is bound up in the (re)creation of environments as they simultaneously affect and are affected by humans.

At its core, I believe that Human Geography ought to be concerned with uncovering these hidden meanings and exposing the underlying values through which environments emerge. If people with dementia and those who require long-term care are living in environments that are somehow robbing them or limiting their personhood, this shows that the individuals in the culture and society that conceptualized and ultimately built those environments either lack an understanding of their needs, or simply don't care. I have not met an individual who doesn't care, and yet, many long-term care facilities represent a dire option for people with dementia and their families perceptually. This disconnect between individual values and environments is at least partly due to the reminder that people with dementia sometimes make us reflect upon our own mortality which is important because generally speaking, society appears to have a deep-seated fear of facing ideas about illness and death and dying which results in a lack of conversation and knowledge translation about these important concerns. A possibility for future research should include further investigating the relationships between individual values, environments for care and dementia care policy in Canada.

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Appendix A. Invitation for Resident Representatives

For Healthcare Representatives of Residents



INVITATION TO PARTICIPATE

The Lived Experience of Person-Centered Care: A Case Study at The Lodge at Broadmead.

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: **kbp@uvic.ca** or by telephone at **(250) 508-0338**.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Health Geography. It is being conducted under the supervision of Dr. Denise Cloutier. You may contact my supervisor at **dcloutier@uvic.ca**.

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care.. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you have a family member and/or represent someone who lives in The Lodge at Broadmead and therefore has an important experience and perspective of the person-centered environment. It is very important for this project that the residents have a voice in their own representation in spite of their cognitive decline. As a result of their cognitive impairment your consent is required on their behalf.

What is Involved

Your consent is required in order to allow me access to conduct an unstructured, conversation-like interview with the resident you represent. I do not require your presence at the interview however you have the option to be present which can be indicated at the end of the consent form. The interview will take place during one of my regular, weekly volunteer shifts on Palm North Lodge. As a volunteer in Palm North Lodge, I have experience communicating with the residents and have formed relationships with many of them. I have also completed the 'Supportive Pathways,' workshop at The Lodge at Broadmead which further illustrates my ability to communicate with older adults with dementia. The interview will proceed as an everyday conversation however, will be recorded and transcribed by the researcher in an attempt to uncover the lived experience in the environment. It will be no longer than 45 minutes.

Risks

It is possible that residents will experience stress, fatigue and/or psychological discomfort as a result of the interview process as their cognitive impairment and social circumstances tend to make them emotionally and physically fragile. To minimize these risks I will have the residents lead the conversation and be very sensitive to their reactions. The interviews are not invasive whatsoever and the only difference between them and our regular conversations is a tape recorder. If at any time I sense that the resident is uncomfortable I will end the interview and comfort the resident in an appropriate way as well as inform a nurse/care aid. I am very attuned to the residents' emotions and will not force anything on them. If a resident shows signs of fatigue or discomfort (physical or emotional) I will immediately end the interview and comfort them in an appropriate manor. I will then consult a nurse/care aid.

Additionally, if residents share with me any incidents of neglect or abuse, I am required to report this to a manager at the facility.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has

successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The resident's perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, the resident may withdraw at any time without any consequences or any explanation. If the resident does withdraw from the study the data will not be used in the analysis and will be disposed of.

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only the research team will have access to the information through password-protected files.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be stored in a locked desk at the University of Victoria. The researcher is the only person who has access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of. Electronic data will be erased and paper copies will be shredded upon completion of the thesis.

Contacts

If you are interested in participating in this very important research project, please contact Kyle plumb at kbp@uvic.ca or (250) 508-0338.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Appendix B. Consent Form for Resident Representatives

For Healthcare Representatives of Residents



PARTICIPANT CONSENT FORM

The Lived Experience of Person-Centered Care: A Case Study at The Lodge at Broadmead.

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: **kbp@uvic.ca** or by telephone at **(250) 508-0338**.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Health Geography. It is being conducted under the supervision of Dr. Denise Cloutier-Fisher. You may contact my supervisor at **dclfisher@uvic.ca**.

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care.. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you have a family member and/or represent someone who lives in The Lodge at Broadmead and therefore has an important experience and perspective of the person-centered environment. It is very important for this

project that the residents have a voice in their own representation in spite of their cognitive decline. As a result of their cognitive impairment your consent is required on their behalf.

What is Involved

Your consent is required in order to allow me access to conduct an unstructured, conversation-like interview with the resident you represent. I do not require your presence at the interview however you have the option to be present which can be indicated at the end of this form. The interview will take place during one of my regular, weekly volunteer shifts on Palm North Lodge. As a volunteer in Palm North Lodge, I have experience communicating with the residents and have formed relationships with many of them. I have also completed the 'Supportive Pathways,' workshop at The Lodge at Broadmead which further illustrates my ability to communicate with older adults with dementia. The interview will proceed as an everyday conversation however, will be recorded and transcribed by the researcher in an attempt to uncover the lived experience in the environment. It will be no longer than 45 minutes.

Risks

It is possible that residents will experience stress, fatigue and/or psychological discomfort as a result of the interview process as their cognitive impairment and social circumstances tend to make them emotionally and physically fragile. To minimize these risks I will have the residents lead the conversation and be very sensitive to their reactions. The interviews are not invasive whatsoever and the only difference between them and our regular conversations is a tape recorder. If at any time I sense that the resident is uncomfortable I will end the interview and comfort the resident in an appropriate way as well as inform a nurse/care aid. I am very attuned to the residents' emotions and will not force anything on them. If a resident shows signs of fatigue or discomfort (physical or emotional) I will immediately end the interview and comfort them in an appropriate manner. I will then consult a nurse/care aid.

Additionally, if residents share with me any incidents of neglect or abuse, I am required to report this to a manager at the facility.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The residents perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

If you do decide to consent, the resident may withdraw at any time without any consequences or any explanation. If you or the resident withdraw from the study the data will not be used in the analysis and will be disposed of.

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only I will be privy to the information through password-protected files.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be stored in a locked desk at the University of Victoria. The researcher is the only person who has access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of. Electronic data will be erased and paper copies will be shredded upon completion of the thesis.

Contacts

Individuals that may be contacted regarding this study include researcher Kyle Plumb. Contact information is listed at the beginning of this document.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Do you wish to be present during the interview? Yes/No (circle one)

_____ (Resident Name)

_____ (Participant Representative to provide initials)

Name of Participant Representative

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix C. Leadership Invitation to Participate

For Leadership



INVITATION TO PARTICIPATE

A Case Study to Explore Person-Centered Care at The Broadmead Lodge, Victoria, BC

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: **kbp@uvic.ca** or by telephone at **(250) 508-0338**.

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you work in a leadership capacity in The Lodge at Broadmead and therefore have an important experience and perspective of the person-centered environment.

What is Involved

If you agree to voluntarily participate in this research, your participation will include a one-on-one interview up to a maximum of one hour in length. The interviews will be recorded and transcribed by the researcher and brief observations will be made to aid in the transcription.

Risks

If residents share with me any incidents of neglect or abuse, I am required to report this to a manager at the facility.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The residents perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used in the analysis and will be disposed of

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only I will be privy to the information through password-protected files.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be

stored in a locked desk at the University of Victoria. The researcher team are the only people who have access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of at the end of three years. Electronic data will be erased and paper copies will be shredded at this time.

Contacts

If you are interested in participating in this very important research project, please contact Kyle plumb at kbp@uvic.ca or (250) 508-0338.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Appendix D. Staff invitation

Staff and Volunteers



INVITATION TO PARTICIPATE

A Case Study to Explore Person-Centered Care at The Broadmead Lodge, Victoria, BC

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: kbp@uvic.ca or by telephone at **(250) 508-0338.**

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you work in The Lodge at Broadmead and therefore have an important experience and perspective of the person-centered environment.

What is Involved

If you agree to voluntarily participate in this research, your participation will include a focus group interview alongside 3 of your colleagues of up to a maximum of one hour in length. The focus groups will be recorded and transcribed by the researcher and brief observations will be made to aid in the transcription.

Risks

There are no known or anticipated risks to you by participating in this research.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The residents perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used in the analysis and will be disposed of.

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only I will be privy to the information through password-protected files. Participants in focus groups will also be asked not to speak about the composition of the group, i.e., names of others in the group or about any information that is exchanged.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be stored in a locked desk at the University of Victoria. The researcher team are the only people who have access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of at the end of three years. Electronic data will be erased and paper copies will be shredded at this time.

Contacts

If you are interested in participating in this very important research project, please contact Kyle plumb at kbp@uvic.ca or (250) 508-0338.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Appendix E. Resident interview Guide

Interview Guide: Residents

Interview #:

Participant:

Date:

Location:

Start Time: End Time:

- Confidentiality explained and assent sought

I am wondering if you would be willing to help me with a research project I'm doing for school about your time here and how we can make it better for you. Do you mind if I record our conversations so that I don't forget what you told me? You can also decide to stop at any time or can choose not to answer questions that you don't want to.

- Questions before we start?

1.) Background Information (intent: increasing knowledge of resident)

- Where are you from? (past)
- What kind of things did you enjoy to do before you came here?
- How long have you lived here? (present)

2.) Experience of TLAB

- 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 Lodge? 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.) Relationships

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

Appendix F. Leadership Consent Form

For Leadership



PARTICIPANT CONSENT FORM

The Lived Experience of Person-Centered Care: A Case Study at The Lodge at Broadmead.

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: **kbp@uvic.ca** or by telephone at **(250) 508-0338**.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Health Geography. It is being conducted under the supervision of Dr. Denise Cloutier-Fisher. You may contact my supervisor at **dclfisher@uvic.ca**

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care.. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you work in a leadership capacity in The Lodge at Broadmead and therefore have an important experience and perspective of the person-centered environment.

What is Involved

If you agree to voluntarily participate in this research, your participation will include a one-on-one interview up to a maximum of one hour in length. The interviews will be recorded and transcribed by the researcher and brief observations will be made to aid in the transcription.

Risks

If residents share with me any incidents of neglect or abuse, I am required to report this to a manager at the facility.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The residents perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used in the analysis and will be disposed of.

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only I will be privy to the information through password-protected files.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be stored in a locked desk at the University of Victoria. The researcher is the only person who has access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of. Electronic data will be erased and paper copies will be shredded upon completion of the thesis.

Contacts

Individuals that may be contacted regarding this study include researcher Kyle Plumb. Contact information is listed at the beginning of this document.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

_____ (Participant to provide initials)

Name of Participant _____ Signature _____ Date _____

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix G. Leadership Interview Guide

Interview Guide: Leadership

Interview #:

Participant:

Date:

Location:

Start Time: End Time:

-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?

1.) BACKGROUND INFORMATION

- Job title and general role in TLAB

- Main elements of job and related background
- How long have they worked in this capacity

2.) INDIVIDUAL UNDERSTANDINGS OF PCC AT TLAB

- "TLAB has adopted an explicitly person-centered approach to care"

- What does PCC mean to them; what do they see the main elements as being?

- What do they see their **role** in enacting PCC as being? (put the principles of PCC into everyday practice).

- Role and Examples

- How do they view the role of direct care staff in enacting PCC?

- Volunteers

- How do they support staff (and volunteers) in this role? (e.g., training, workshops, experience).

- "the knack"

- what are the personal qualities/traits in staff/volunteers that they feel best support PCC?
 - . 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 PCC?

- Examples

3.) CHALLENGES TO IMPLEMENTATION OF PCC

- What do they see as the main challenges of operationalizing PCC?

- time, staff, funding, communication

- If they lived at TLAB as a resident, what do they think their likes and dislikes would be?

- regarding physical, social, psychological environment
- assume unlimited \$
- would they want to change anything? What would they want to change?

- Anything that they feel I have missed or haven't had the chance to say regarding their experience at TLAB and with PCC?

Appendix H. Staff Consent Form

For Staff



PARTICIPANT CONSENT FORM

The Lived Experience of Person-Centered Care: A Case Study at The Lodge at Broadmead.

You are invited to participate in a study that is being conducted by Kyle Plumb, a Graduate student in the Geography department at the University of Victoria. You may contact him if you have any further questions at: **kbp@uvic.ca** or by telephone at **(250) 508-0338**.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Health Geography. It is being conducted under the supervision of Dr. Denise Cloutier-Fisher. You may contact my supervisor at **dcloutier@uvic.ca**

Purpose and Objectives

The purpose of this research project is to get a better understanding of the relationship between people that live and work in The Lodge at Broadmead (TLAB) and the person-centered environment that has been put in place there. The perspectives of leadership, staff and residents will be compared and contrasted to get an overall sense of what it's like to live or work in a residential care facility that has implemented a person-centered philosophy care. People with dementia are often ignored in the discussion of their care due to stigmatization about their cognitive impairment. This study aims at giving them a voice in their care environment which, along with the voice of the staff and leadership, can help to inform an environment that is person-centered and ultimately increase the quality of care.

Importance of this Research

Research of this type is important because the results will help to inform health care policy and society-wide attitudes about dementia; contribute to the theory and applications of person-centered care, as well as the cultural shift in caretaking facilities; and give voice to the residents, staff and volunteers who are at the forefront of the cultural shift towards a person-centered focus in dementia care.. The results will also be of use for TLAB to incorporate into their education system in the future and for other organizations that have adopted, or that wish to adopt a more person-centered approach to the services they provide. This research is of use to TLAB as it provides them with the perspective of someone who is outside the facility and an analysis that is health geography oriented.

Participants Selection

You are being asked to participate in this study because you work or volunteer in The Lodge at Broadmead and therefore have an important experience and perspective of the person-centered environment.

What is Involved

If you agree to voluntarily participate in this research, your participation will include an interview possibly alongside 3 of your colleagues of up to a maximum of one hour in length. The interviews will be recorded and transcribed by the researcher and brief observations will be made to aid in the transcription.

Risks

If residents share with me any incidents of neglect or abuse, I am required to report this to a manager at the facility.

Benefits

For residents, the primary benefit is a higher quality of care for residential populations with dementia. This project gives the residents an opportunity to have a voice regarding their environment which is often ignored due to stigma about their cognitive impairment. Similarly, for staff and volunteers benefits include the opportunity to contribute to the philosophy of care and care environment that they work/volunteer in. Both of these benefits translate into an empowerment for these groups as they are able to have a voice in their work or living environments. For leadership, the main benefit is to be provided with a perspective of the facility and their philosophy of person-centered care that is from the realm of health geography and is outside of the facility. Moreover, the similarities and differences in perspectives of person-centered care between and within participant groups at TLAB will provide leadership with helpful information about attitudes within the facility which they can then give back to the staff, volunteers and residents via educational presentations.

For society, this study will contribute to the cultural shift towards a humanistic and person-centered approach to dementia care. By providing an example of one facility which has successfully operationalized a philosophy of person-centered care this study can help consult other facilities about the philosophy itself and its possible therapeutic outcomes for residents.

The state of knowledge will benefit from an inquiry into the role of the physical environment in person-centered dementia care. Presently there is little information about this aspect of the environment and how it can affect the quality of dementia care. As well, research has tended to leave out the perspective of residents with dementia due to stigma about their cognitive impairment. This project will give them a voice and allow them to provide their views about the environment they live in by conducting open-ended interviews using specialized communication methods. The residents perspective on their own care environment will help to give this project a well-rounded and nuanced view of the lived experience of person-centered care and the influence of the physical environment that is not currently available.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used in the analysis and will be disposed of.

Anonymity

The anonymity of participants will be ensured through the use of pseudonyms in the interpretation and reporting of the data. Confidentiality will be preserved by limiting access to the data so that only I will be privy to the information through password-protected files. During the focus group, you will be asked not to speak about the composition of the group, i.e, names of others in the group or about any information that is exchanged.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by storing it in password protected files on a computer at the University of Victoria. Hard copies of transcriptions will be stored in a locked desk at the University of Victoria. The researcher is the only person who has access to the data.

Dissemination of Results

It is anticipated that the results of this study will be disseminated as a published article, thesis/dissertation, presented at scholarly meetings as well as presented back to the participants at TLAB

Disposal of Data

Data from this study will be disposed of. Electronic data will be erased and paper copies will be shredded upon completion of the thesis.

Contacts

Individuals that may be contacted regarding this study include researcher Kyle Plumb. Contact information is listed at the beginning of this document.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

_____ (Participant to provide initials)

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
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A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix I. Staff interview Guide

Interview Guide: Staff

Interview #:

Participants:

Date:

Location:

Start Time: **End Time:**

-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 focus group will take approximately 45-60 minutes. (It will likely be longer so give yourself time).

-Do you have questions before we proceed?

1.) INDIVIDUAL UNDERSTANDINGS OF PCC AT TLAB

- "TLAB has adopted an explicitly person-centered approach to care"
- What does PCC mean to them; what do they see the main elements as being? Discuss.
- What do they see **their role** as being in enacting PCC? Examples
- How are they supported or not by leadership in this role?
 - education, training, emotional, physical
 - probe job satisfaction
 - What do they know about residents? How do they develop relationship? How important is it to develop relationship? Do they have enough information about residents' past lives?
- "the knack"
 - what are the personal qualities/traits in staff/volunteers that they feel best support PCC?
 - . Can this be achieved through training? or is it innate? Job satisfaction?
- What role(s) do they feel that the physical environment plays in the implementation of PCC? Role first and then
 - Examples.

3.) CHALLENGES TO IMPLEMENTATION OF PCC

- What do they see as the main challenges of operationalizing PCC?

- time, staff, funding, communication
- do they have enough time to build meaningful relationships with the residents?

Q) IDEAL CONDITIONS- If they lived at TLAB as a resident, what do they think their likes and dislikes would be

- regarding physical, social, psychological environment
- assume unlimited \$
- would they want anything changed?

- Anything that they feel I have missed or haven't had the chance to say regarding their experience at TLAB and PCC.

- Reaffirm Confidentiality