CHALLENGES OF PERSON-CENTRED DEMENTIA CARE:
A CRITICAL ETHNOGRAPHY OF CULTURE CHANGE IN LONG-TERM CARE

by

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ABSTRACT

To address shortcomings in traditional long-term residential care (LTRC), facilities are increasingly adopting person-centred care (PCC) approaches. Despite the proliferation of PCC models and discourses, there is limited understanding in gerontology of how such approaches are experienced on the ground. This dissertation addresses this gap through an ethnographic study of Cedar Grove, a large facility located in an urban centre in Western Canada that is undergoing culture change. During 12 months of fieldwork, I explored the range of issues this organization encountered as it endeavours to maintain the “person” at the centre of care. The purpose of this study is to contribute empirical data on how this orientation shapes daily life for residents, families, staff and administrators.

This study is informed by the literatures of PCC and personhood theory, and it draws on a conceptual framework integrating critical, feminist and Foucauldian gerontology. It analyzes care across personal, interpersonal, and organizational levels, and considers the broader social-political-economic context of LTRC. Data generation employs multiple methods: participant observation, Dementia Care Mapping (DCM), group meetings, individual interviews, researcher-produced photographs, and a review of relevant organizational and policy documents.

Findings reveal organizational tensions between ideals of safety and PCC, multifaceted challenges to relational care, and the importance of everyday activity toward social inclusion. Data suggest five key implications: 1) Intersectionality highlights residents’ disparate access to social inclusion and ways to support more heterogeneous populations, 2) Increased access to unstructured, everyday activity might address boredom and foster meaning in residents’ lives, 3) Job descriptions might better prioritize social care and
flexibility in work roles to better address issues of time constraints, workload, and resident acuity, all of which challenge PCC, 4) Organizational support for narrative-based biography is vital to overcoming systemic barriers to its use in practice. Finally, 5) A methodological implication of this study relates to how DCM facilitated insight into residents’ non-verbal expressions of personhood and bodily, affective communications. The mobilization of this research to practice during fieldwork highlights DCM’s ability to convey positive practice skills in a way that supports uptake, positively impacting residents’ quality of life.
PREFACE

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# TABLE OF CONTENTS

ABSTRACT .......................................................................................................................... ii

PREFACE .............................................................................................................................. iv

TABLE OF CONTENTS ......................................................................................................... v

ACKNOWLEDGEMENTS ........................................................................................................ x

CHAPTER 1: INTRODUCTION: BACKGROUND AND SIGNIFICANCE ......................... 1

Research Problem .............................................................................................................. 6
  Study Implications .......................................................................................................... 6
  Study Purpose and Objectives ...................................................................................... 9
  Dissertation Overview ................................................................................................... 9

CHAPTER 2: REVIEW OF SELECTED LITERATURE .................................................. 12

Problematizing Traditional Care .......................................................................................... 13

Transforming LTRC .......................................................................................................... 16
  The Role of Personhood ................................................................................................. 16
  The Role of Person-Centred Care ................................................................................ 19
  Culture Change Models ................................................................................................. 21

Applying Theory in Practice ............................................................................................. 23
  Communication Skills Training in Person-Centred Dementia Care ......................... 25
  Resident Biography ...................................................................................................... 27

Challenges to Culture Change in LTRC ........................................................................... 31
  Staffing Levels and Quality of Care ............................................................................ 31
  Defining Quality of Life ................................................................................................. 34

Expanding Concepts of Personhood and PCC—Conceptual Issues to Date ............... 36
  Embodiment .................................................................................................................. 36
  The Physical Environment ............................................................................................ 37
  Agency ............................................................................................................................ 39
  Relationship-Centred Care ........................................................................................... 40

Ethics in Person-Centred Care .......................................................................................... 43
  I/Thou and I/It Modes of Relating ................................................................................ 44
  Intentional and Non-Intentional Modes of Relating .................................................... 45
Activity, Social Inclusion, and Exclusion in LTRC .................................................. 47
Factors in Social Exclusion ......................................................................................... 49
Successful Aging and Activity ...................................................................................... 51
Activity, Well-Being, and Dementia in LTRC ................................................................. 54
Chapter Summary ........................................................................................................ 59

CHAPTER 3: CONCEPTUAL FRAMEWORK ..................................................................... 61
Critical Gerontology ....................................................................................................... 61
Foucauldian Gerontology ............................................................................................... 63
Feminist Gerontology ..................................................................................................... 70
Changing Culture: The “Person” in Care ....................................................................... 75

CHAPTER 4: RESEARCH DESIGN .................................................................................... 78
Methodology: Critical Ethnography ................................................................................ 79
Research Process ............................................................................................................ 82
Entering the Field ............................................................................................................ 82
Study Site Description .................................................................................................... 84
Philosophical Orientation at Cedar Grove ..................................................................... 85
Study Sample and Sampling Approach .......................................................................... 86
Recruitment and Consent ............................................................................................... 91
Data Generation ............................................................................................................. 93
Participant Observation .................................................................................................. 95
Shadowing ...................................................................................................................... 100
Summary of PO at Cedar Grove ................................................................................... 100
Visual Data: Researcher-Produced Photographs ................................................................ 101
Dementia Care Mapping .................................................................................................. 103
Group Meetings .............................................................................................................. 107
Individual Interviews ..................................................................................................... 109
Review of Relevant Documents ..................................................................................... 111
Data Analysis and Interpretation .................................................................................... 111
Introduction .................................................................................................................... 111
Data Analysis ................................................................................................................ 114
Coding and Thematic Analysis ....................................................................................... 115
Analytic Lens: Citizenship .............................................................................................. 116
Analytic Lens: Intersectionality ..................................................................................... 117
DCM Interpretation ........................................................................................................ 119
Document Review and Discursive Practices .................................................................... 120
Establishing Trustworthiness ......................................................................................... 122
Reflexivity ...................................................................................................................... 122
Power and Reflexivity in the Interview Process ............................................................. 124
CHAPTER 5: THE SOCIAL WORLD OF CEDAR GROVE: RESIDENT VIGNETTES

Holly Street: Emilia, Fran, Hazel and Eva

Juniper Way: Hannah, Ruth, and Maria

Chapter Summary


Resident Safety: Exploring Policy and Practice at Cedar Grove

Introduction

Beyond Eden: The Impact of Care Philosophy

The Structure of Safety: Stigma, Dementia, and Levels of Care

“Challenging Behaviours”

Preventing Falls: “Keep Mum Safe!”

Surveillance and Space

Mitigating Social Isolation: The Role of Private Companionship

Preventing Conflict

Ethical Issues: Power, Advocacy, and the Role of the RCA

Cedar Grove Staff: Physical Safety at Work

Lifts and Slings: A Bathing Care Encounter

Evaluating Risk: Resident Im(mobility)

Technological Supports and Policy Changes: Impact on the Ground

“There’s no time for kind, calm caring”: Time Constraints and Workload

“Aggression” and “Violence”: A Vision for Prevention in Practice

Collective Safety: Outbreaks, Quarantine and Infection Control

Chapter Summary

CHAPTER 7: CULTURAL PERSPECTIVES ON CARING: THE SIGNIFICANCE OF RELATIONSHIPS AT CEDAR GROVE

Resident Perspectives on Relationship in Care

Dementia Care Mapping Data on Relationships in the SCU

Staff Perspectives on Relationships in Care
Dementia Care Mapping Data: Staff Perceptions of Implications for Practice ............... 233
Exploring the Digital Divide: Computer Access, Literacy, and the Role of the RCA... 238
Job Descriptions: The Duties and Responsibilities of the RCA ........................................ 241
Administrative Perspectives on Culture Change: “It’s not the what, but the how”........ 244
Achieving a Caring Culture: Promoting a Team Approach .............................................. 245
Organizational Documents and the Language of Care ..................................................... 249
Family Perspectives of Relational Care ........................................................................... 253
Chapter Summary ........................................................................................................ 260

CHAPTER 8: UNSTRUCTURED ACTIVITY AND SOCIAL ENGAGEMENT ............... 263

Resident Views on Activity and Social Engagement:
Barriers to Participation .................................................................................................. 264
Everyday Activity and “Reality TV”: Watching Television Together............................. 267
Television, Dementia Care, and Power: Who’s in Control of the Remote? ..................... 273
Food and the Dining Experience: Everyday Meals, Unstructured Activity, and
Celebrations ...................................................................................................................... 275
   Everyday Dining: Menu Options, Costs, and Subjective Taste .................................. 276
   The Dining Experience and Socialization .................................................................. 278
   Celebrating with Food ............................................................................................... 281
   Food Safety .............................................................................................................. 282

“Leisure” Reconsidered .................................................................................................... 283
   Residents-Resident Interactions in Unstructured Time:
   Relational Gestures on the SCU .............................................................................. 287
Chapter Summary ........................................................................................................ 291

CHAPTER 9: DISCUSSION .......................................................................................... 293

Residents’ Social Worlds: An Intersectional Analysis ................................................... 294
Safety First: Space, Power, and Organizational Practices at Cedar Grove.................. 303
   Making Decisions: Establishing Best Interests and Gaps in Practice .................... 311
Challenges to Relational Care Practice ......................................................................... 315
   1) Workload, Resident Acuity, and Job Descriptions ............................................... 315
   2) Staff Hierarchy and Lateral Power ....................................................................... 318
   3) Finding the Right Message: “Serving Tea” as “Actual Work” ............................... 320
   4) The Use of Resident Biography in Practice ......................................................... 322
Fostering Relational Care Practices: Philosophical Considerations .............................. 324
Finding Meaning in the Everyday .................................................................................. 331
   Television Use in Long-Term Care ........................................................................... 334
CHAPTER 10: CONCLUSION AND STUDY IMPLICATIONS ........................................... 348

Study Implications ........................................................................................................ 350

Overcoming Organizational Barriers—Employing an Intersectional Perspective ..... 351

Valuing Everyday Activities—Supporting Well-Being and Social Inclusion .......... 352

Supporting Relational Practice .................................................................................... 354

Using Biography in Care Practice ............................................................................. 355

Mobilizing Knowledge—Toward Person-Centred Care Practice ............................... 357

Balancing Needs: Working to Keep “the Person” at the Centre of Care ................. 359

REFERENCES ............................................................................................................. 363

APPENDICES ............................................................................................................... 415

Appendix A: Site Photographs .................................................................................... 416

Appendix B: Research Poster ..................................................................................... 420

Appendix C: Presentation Evaluation Form ............................................................... 421

Appendix D: Sample DCM Chart ............................................................................. 422

Appendix E: Sample Consent Form ........................................................................... 423
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In spite of this, her gestures, her smile, her voice remained unchanged. A blurred version of her charm survived, together with hints of a sense of humour. She was suffering a disturbance of her soul, not just a loss of memory, yet she was still intact.

—M Ignatieff Scar Tissue (1993)
CHAPTER 1:
INTRODUCTION: BACKGROUND AND SIGNIFICANCE

Ageism is prevalent in the media, in our health care and in our social systems whereby growing older is constructed as a social problem based on inevitable decline and loss. The inclusivity of aging sets it apart from other prejudices based on differences of gender, race, or ability. Paradoxically, ageism is predicated on an unacknowledged fact that the majority of people from the “in-group,” that is young people, are growing old and will eventually (if they are lucky) enter the “out-group” (Nelson, 2004, p. x). Old age is held as a marker of difference, yet it cuts across almost all socially ascribed categories of difference, compounding disparities based on race, class, sexuality and ability. Discrimination based on age has been called one of the most socially condoned and institutionalized forms of prejudice in the world (Nelson, 2004). The idea of old people functions to remind the young of their own mortality. Many people seem to feel that old age is something that happens to someone else; however, as Tinney (2008) so eloquently puts it, “The only difference between them [old people] and us is they got there first. And that’s it” (p. 223). Indeed it is because an increasing number of us are, baring illness or accident, reaching “the fourth age” (Baltes & Smith, 2003) that the pursuit of optimal care and living situations toward the end of life is in the interest of all Canadians. Not only will we grow older, but so too will our family and friends, making it in our collective best interests to attain long-term care that is able to meet our social, emotional, and physical needs – and rights.

In Canada and throughout the world, the health and social welfare of older adults has emerged as a significant challenge in the face of global economic fiscal restraint. Debates
ensue over the ability of societies to pay for the increased costs typically associated with older age. This widespread fear of a demographic shift toward an aging population in Western nations is marked by pejorative references to ‘the gray wave” or “silver tsunami” and dire predictions about the social, economic, and political consequences of an aging post-War generation (i.e. baby boomers). These predictions signal to some “alarmist demography” (Katz, 1992) or “apocalyptic demography” (Robertson, 1990, 1997) that serve particular political agendas allowing for further marginalization and ultimately the abuse of older adults. At a macro level, response to aging populations tends to centre on negative questions such as: How will society cope with an aging workforce? What will we do with growing numbers of healthcare consumers? How can the economy cope with the increased strain on resources? Older adults are seldom seen in terms of their contributions to society. On the level of the individual, the effects of dire demographic predictions might be described as twofold: 1) older adults are stigmatized and marginalized in social interactions, which often exacerbates other problems, and 2) older adults internalize negative characterizations of their own productivity or independence and often begin to see their own lives in terms of increased fragility, frailty, and loss (Burgener & Berger, 2008; Dobbs, Eckert, Rubinstein, Keimig, Clark, Frankowski, & Zimmerman, 2008; Goffman, 1963/1986; Moss & Moss, 2007; Twigg, 2004).

Ageism is often associated with what appears to be a fear of dementia. This fear is not entirely unfounded. In Canada, as in most of the industrialized world, the likelihood of developing dementia increases with age: after the age of 85, the disease affects one in three seniors (Statistics Canada, 1996). Thus, statistically speaking, advanced age represents a key risk factor for dementia; the longer one lives the more likely one is to develop it. It is worth
noting, however, that this statistic also reveals that two-thirds, the majority, of our oldest-old citizens does not have dementia. Yet, despite this demographic fact, it is the negative ideas and attitudes about advanced age that remain prevalent in the public sphere (Levy & Banaji, 2004; Whitbourne & Sneed, 2004).

Inasmuch as growing older does not equal dementia, the dominant social construction of Alzheimer disease (AD), in particular, rests on a correlation of age with increasing forgetfulness, dependency, and loss of selfhood, which has contributed to widespread anxiety and fear. As Milne (2010) succinctly states, “the ‘D’ word” is “a profoundly stigmatizing condition” (p. 231). Herskovits (1995) asserts, “With the popularization of Alzheimer's, the subjective experience of aging and of ‘senility’ have become increasingly horrific and monstrous; we are all afraid of losing our minds as we grow old” (p. 148).

Now approximately 30 years beyond the beginnings of the “Alzheimer’s disease social movement” (Fox, 1989; Lyman, 1989; McLean, 2007b), perhaps nowhere are ageism and the stigmatization of older people more evident than in relation to the characterization of people with dementia. The largely (Western) negative conceptualization of aging itself and its impact on dementia care significantly influences societal responses to the care needs of older adults, and this reality serves as the jumping off point for this critical ethnography. It has been over a decade since Katz (1996) called for a critical gerontology that expands its focus from the individual to the social and political context in which we age. Katz (1996) critiques these types of cultural representations and calls on mainstream gerontologists to examine their own practices and biases in knowledge production: “The aim is to go beyond an understanding of what gerontology says and grasp what gerontology does in the world of aging” (p.7).
Our demographic shift has profound implications for “what gerontology does” and our need to do more, particularly in relation to long-term residential care (LTRC). Upon entering a Canadian facility, one is likely to notice that people are older and generally sicker than was once the case. Specifically, people who move to residential settings are increasingly more likely to have dementia, to be functionally dependent, and to be closer to the end of their lives (McGregor & Ronald, 2011). These demographic changes place greater demands on direct carers (Banerjee, Daly, Armstrong, Armstrong, Lafrance & Szebehely, 2008). Resident populations are also more heterogeneous than they have been historically. The shift in the resident profile has occurred in a context in which traditional, biomedically-driven models of care have been criticized for their inability to extend care beyond the provision of medical care and adequately address the psychosocial context of care (Chenoweth, King, Jeon, Brodaty, Stein-Parbury, Norman, Haas & Luscombe, 2009; McLean, 2007b; Woods, 2001). This deficit-focused traditional care has been accused of failing to recognize residents’ individual needs and preferences, offering instead a cookie-cutter or one-size-fits-all approach that serves no-one well (Lyman, 1989; Kitwood & Bredin, 1992; Parker, 2001).

Since the 1990s, in response to increasing criticism of traditional care, residential care has begun to shift away from the biomedical model toward care that is philosophically grounded in person-centred care (PCC) approaches (Brooker, 2004; Innes, 2009; Martin & Younger, 2001). Influenced significantly by the scholarship of Tom Kitwood on personhood and dementia, there has been a proliferation of PCC models that emphasize a more positive conceptualization of dementia, the subjective experiences of dementia, and the importance of social processes on well-being and quality of life in LTRC. The Eden Alternative, the Pioneer Network, and Gentlecare are a few examples of models that have adopted person-
focused philosophies in North America. This focus does not negate the serious implications of dementia on the person or his or her social network. Rather, it advances the importance of considerations of the “totality of the person” (Sabat, 2011, p. 96) through recognition of the interplay of bio-psycho-social forces on a person’s experience of dementia. Proponents of the new “culture of care” (Kitwood, 1997; Ronch, 2004) associated with PCC advocate for a departure from task-based, custodial care that prioritizes “bed-and-body work” (Gubrium, 1975/1997) to relational care (Nolan, Davies, Brown, Keady, & Nolan, 2004) that endeavours to foreground the personhood and interconnectedness of residents, their families, and care staff. Proponents of personalized modes of caring counter notions of hopelessness and despair with the proposition that given positive relationships and a supportive social milieu persons with dementia can in fact achieve relative levels of well-being (Kitwood, 1990/2007, 1995/2007; Kitwood & Bredin, 1992).

This study grapples with the fact that, despite the so-called “nursing home culture-change” (Rahman & Schnelle, 2008), LTRC continues to be considered as a site of social and physical segregation for residents and care staff where women in low-paid, low-status positions tend to bear the burden of caring for the complex needs of very frail, vulnerable residents, the large majority of whom are women (Diamond, 1992; Eckenwiler, 2011; Gubrium, 1975/1997; McLean, 2007a; Reed-Danahay, 2001; Vesperi & Henderson, 1995). Notwithstanding the popularity of person-centred models, evidence of high staff turnover rates, low job satisfaction, and stigma associated with LTRC continues. Moreover, residents continue to report personal experiences of social isolation, inactivity and boredom, all key detractors from quality of life (Ice, 2002; Schreiner, Yamamoto, & Shiotani, 2005). Residents still spend their days under-stimulated and without any activity (Cohen-Mansfield,
The overwhelming quantity of research on PCC indicates that such approaches are seen to offer a vital potential for appropriate and humane dementia care. Certainly the volume of research in this area suggests that any investigation of dementia care in institutional settings should include an exploration of the extent to which LTRC facilities implement person-centredness. It seems that in spite of the widespread adoption of a language that reflects person-centred rhetoric in LTRC (Brooker, 2004), the social, economic, and political context continues to perpetuate a disease-focus of care in which quality of life issues are ancillary to medical care. With respect to Canadian legislation around LTRC, Coughlan and Ward (2007) point out that in general, despite Canadian’s general agreement about the importance of universal health care, the Canada Health Act does not cover nursing homes. Rather, as these researchers demonstrate, LTRC in Canada is not federally regulated and as such it is currently determined by “differing legislation and funding criteria reflecting ideological commitments in each province or territory” (Coughlan & Ward, 2007, p. 44).

**Research Problem**

Long-term care facilities have been described as businesses—with residents depicted as health-care consumers, customers, or clients—within a health-care industry led by market forces and a profit motive (Baars, 2006; Diamond, 1992; Gubrium, 1975/1997; Vesperi, 1995). Coinciding with broader socio-political contexts, the pervasive influence of ageism, societal fears, and stereotyping associated with age and dementia, are factors in inadequate funding of LTRC (McLean, 2007b). These forces impact residents, staff, administrators and
the overall “culture of care” in complex and interrelated ways. For residents, the need to improve quality of life is a pressing concern (Reid, Chappell, & Gish, 2007), yet we lack understandings of what constitutes quality of life in residential settings (Kane, 2001), especially for persons with dementia (Moyle, McAllister, Venturato, Adams, 2007).

Moreover, although theory supports the value of person-centred approaches, how this focus makes a difference at the level of practice in the day-to-day life of residents is not clear. Research points to a lack of appropriate training and low status for formal carers who work with older adults with dementia (Brooker & Surr, 2005; Nolan et al., 2004). Both residents and care workers share struggles with respect to disempowerment, disenfranchisement, and disconnection from a wider society. Administrators face pressures in relation to the business of LTRC, regulatory structures, and providing for the increasingly complex care needs of residents alongside managing front line workers.

Long-term residential care exists within sociopolitical contexts where organizational policies and institutional practices are accused of being at odds with PCC outcomes. Person-centred care has been proposed as a holistic alternative to conventional care that strives to address the innumerable challenges of LTRC (Brooker & Surr, 1995; Hughes, Louw, & Sabat, 2006; Kitwood, 1997; Woods, 2001). Nevertheless, there is the suggestion in the literature that a dichotomy exists between the real work of LTRC and social care. Disparities seem to exist between the various regulatory practices that are seen to prioritize the needs of the industry and the institution over for example, quality of life domains, such as comfort, meaningful activity, autonomy, and relationships (Boyle, 2008; Kane, 2001). Hence, critics of policy decisions that have resulted in the widespread adoption of person-centred models claim they are misguided because they focus to a large extent on the individual experience of
dementia while failing to consider wider socio-political forces that influence LTRC environment (Nolan et al., 2004; McCormack, 2004). These models are also charged with placing “huge demands on family carers and paid care workers” (Innes, 2009, p. 49).

Ultimately, the question is whether the widespread influence of person-centred philosophies have created positive change in LTRC living and working conditions.

Moving beyond considerations of culture change through the binaries of evaluation—good vs. bad care, personal or impersonal care—this study explores over time the range of issues that a LTRC facility encounters over time as it endeavours to integrate the tenets of person-centredness, to move theory into practice. My research seeks to describe and interpret the impact of PCC principles on frontline care. The basis of this study relates to the assertion that in spite of a lack of conceptual clarity and critiques of PCC that relate to practice, an increasing number of care facilities define themselves as person-centred and yet little is known about how this orientation is experienced on the ground (Lopez, 2006a).

Using a critical, ethnographic approach, this study sheds light on this vital area of LTRC and dementia care research by describing and interpreting day-to-day life in a residential setting that espouses a person-centred philosophy of care. It presents data from the perspectives of the various constituent groups that comprise the culture of care in relation to the personal, interpersonal and structural components of care, exploring how these spheres overlay, interact and conflict to shape experiences of LTRC. The declaration that “Person-centredness is now clearly on the agenda as a result of his [Kitwood’s] work (although, not necessarily interpreted as Kitwood intended)” (Baldwin & Capstick, 2007a, p. xix) warrants exploration. Although there is considerable theoretical research on the value of PCC, there is paucity of empirical research that indicates its potential to improve LTRC. This study
proposes to fill this research gap by providing an in-depth analysis of a LTRC facility that endeavours to put the “person” at the centre of care.

**Study Implications**

The implications of this study are wide-ranging. Firstly, this study offers critical insights into the experiences and perspectives of long-term care residents, in particular, persons with dementia. Views of residents on aspects of care that so profoundly impact their everyday are too seldom acknowledged and therefore are not adequately represented in policy and practice (Cahill, Begley, Topo, Saarikalle, Macijauskiene, Budraitiene, Hagen, Holthe, Jones, 2004; Dewing, 2002; O’Connor, Phinney, Smith, Small, Purves, Drance, Donnelly, Chaudhury, & Beattie, 2007; Train, Nurock, Kitchen, Manela, & Livingston, 2005). This study also presents the challenges and rewards to staff that provide direct care to residents. Findings from this study will result in the development of clinically-relevant dementia care research to contribute to enhanced knowledge translation in care practice and inform policy to positively affect long-term health care services available to a marginalized population of older adults and direct carers. Finally, this study has important implications more broadly to contribute to theoretical knowledge in relation to personhood, person-centred care and the transformation of a culture of care.

**Study Purpose and Objectives**

This critical ethnography used multiple qualitative research methods to explore the contention that despite the pervasiveness of person-centred approaches to care, which suggests widespread support of its tenets, research indicates an enduring disconnect between the philosophy underpinning such approaches and the day-to-day realities of LTRC. I wanted
to investigate how a long-term residential care facility that foregrounds the “person” influences culture members’ experiences of daily life and the social world in which they live or work.

This study was led by the following research objectives:

1) To describe the culture of care within a LTRC facility that is organizationally committed to a person-centred philosophy of care.

2) To explore how staff, residents, and family members experience the philosophy of care.

3) To understand how resident biography is understood and functions in this facility.

4) To identify marco-level, socio-political influences on organizational practices and policies that facilitate and/or impede a person-centred philosophy of care.

5) To contribute to understandings of the ability of PCC to mitigate impediments in LTRC and address suboptimal dementia care.

6) To positively affect the living and working situation within LTRC through the production and dissemination of knowledge in relation to PCC.

Dissertation Overview

In this chapter I have introduced the study detailed in the next nine chapters by presenting its background and significance. This chapter has also set out the research problem, study implications, its purpose and objectives. In Chapter 2, I present a review of the relevant literature to provide context for this investigation. Chapter 3 presents the conceptual framework and the overall research design and methodology are detailed in Chapter 4. Study findings are detailed in four chapters. Chapter 5 presents five vignettes
based on the residents I encountered during fieldwork. In Chapter 6 I describe the vital role that safety plays in the culture of care, shaping the lives of the people who live and work at Cedar Grove. Chapter 7 focuses on the significance of relationships for members of the care culture. The final findings chapter presents data on unstructured activity and social engagement, providing insights into how people at Cedar Grove found meaning in their day-to-day life. Chapter 9 presents a discussion of this investigation’s findings. The final chapter in this dissertation provides its concluding remarks and study implications.
CHAPTER 2:
REVIEW OF SELECTED LITERATURE

As this literature review demonstrates, there is considerable theoretical research on the need for and potential value of a person-centred approach toward improved long-term residential care. My review of this literature began formally with the initial research proposal, was expanded during data generation, and finalized in the data analysis and writing stage of this dissertation. As an inductive investigation, emergent findings compelled me to broaden the scope of this literature review into research areas that I had not anticipated at the outset of this study.

The purpose of this review is to present a comprehensive summary and critical analysis of the gerontological literatures which broadly pertain to aging, dementia, long-term residential care, and person-centred care. I examine a body of literature that provides the theoretical foundation of this study, while attempting to identify gaps in the research and underscoring the need for this and future studies in the field. The main body of work considered spans the years 1995-2012. However, I also consider influential texts and seminal works from earlier periods. Keywords for this review include dementia, dementia care, Dementia Care Mapping, personhood, long-term care, person-centred care, relationship-centred care, biography, culture change, self, social care, special care units, meaningful activity, ethnography, critical ethnography and critical gerontology.

This chapter opens with discussion of the social construction of dementia and its relationship to traditional long-term care. Next, I review research devoted to the transformation of LTRC, focusing on discussions of the role of personhood, person-
centred care (PCC) theory, and culture change models that seek to implement person-centric philosophies of care. This is followed by an examination of the research on the challenges of applying person-centred theory in care practice. Key facets of PCC practice developed here pertain to communication skills training for carers and the use of biography to facilitate staff-resident communications in LTRC. I then review research on staffing levels, quality of care and quality of life, which lays the groundwork for a review of the conceptual strengths and limitations of the concepts of personhood and PCC as they are addressed in the research to date. Specifically, I look at research on embodiment, the physical environment, agency, and relationship and how each is considered in relation to a person-centred philosophy of care. This is followed by a review of the literature on ethics and ethical relationships in formal care settings. The final section addresses the gerontological literature on issues of social inclusion and social exclusion in LTRC and looks at notions of successful aging, activity, and meaningful activity in the context of dementia. This chapter concludes with a summary of the selected literature reviewed here.

**Problematizing Traditional Care**

The literature contains many ways to conceptually approach long-term residential care. A traditional approach, often described as biomedical, has dominated the field and more recently social constructionist approaches, such as through the concept of personhood, have been influential. In the Foucauldian sense of problematization (Foucault, 1998), the next few paragraphs are devoted to how and why traditional approaches to long-term care are critiqued in gerontological research. I look at how
“‘things’ came to be” (Bacchi, 2012, p. 7) in dementia studies. This exploration sets the stage for a critical review of the concepts of personhood, person-centred and relational care, and certain approaches that have become influential in the field.

That traditional approaches to LTRC are failing to meet standards of care and quality of life, particularly for persons with dementia, is at this point in history well established (Moyle, Venturto, Griffiths, Grimbeek, McAllister, Oxlade & Murfield, 2011; Popham & Orrell, 2012). Expectations of the demographic shift toward an aging population in industrialized nations, the social, economic and political consequences of a burgeoning “third age” and “fourth age” (Gilbert, 2006) have raised fundamental concerns around how best to meet the needs of a growing portion of the population in relation to LTRC. Contrary to popular fear mongering that typically surrounds this shift in demographics, especially around dementia, research points to both the need and opportunity to participate in a more positive trajectory for LTRC. Gilbert (2006) comments on a new dimension of today’s aging population, namely, a general resistance to complacency: “It holds higher aspirations for standards of living and life opportunities in later life than any prior generation and possibly any generation to come” (p. 75). This social force and concomitant political power possessed by future cohorts that Gilbert (2006) alludes to maps the multifaceted terrain of LTRC. Optimistically, research on aging in general and LTRC in particular, suggests potential for significant change.

The literature shows that current conceptions of dementia have extensive socio-cultural roots. The etymology of the term “dementia” actually dates back to the 1st century A.D. and stems from the Latin word *demens*, which means to be out of or to have lost one’s *mens* or mind (Aquilina & Hughes, 2006). The ramifications of the word
“dementia” on the subjective experience of the disease are varied. Since this disease was first described, it has become increasingly prevalent in thinking about individuals who reach old age. In our consumer driven, youth oriented societies, older adults face discrimination not only because of negative conceptions of old age—assumptions about older adults’ lack of productivity and corresponding burden on society (Twigg, 2004)—but also because of a growing and pervasive fear of Alzheimer disease (AD). Foucault’s (1963/2003) work on the historical origins of biomedicine and dominant social constructions around disease is important to this discussion. Foucault (1963/2003) outlines how, with the development of modern medicine, the scientific or “empirical gaze” (p. xv) functioned to construct a language of supreme power or authority over individual bodies. The contention that “one could at last hold a scientifically structured discourse about an individual” (Foucault, 1963/2003, p. xv) has important ramifications for individuals who are deemed sick or incompetent, and helps explain the objectification of people with dementia. In Western cultures, the medical gaze has helped produce a relatively unproblematized linking of age and dementia, what might be considered in terms of the normalization of the disease that is perhaps one of the most noteworthy features impacting the ways in which dementia is socially constructed.

Often, media attention and public concerns about dementia and dementia care centre on issues of safety. Dewing (2006) suggests that we live in a world that is increasingly “more risk-averse and more litigious and yet one where human rights are supposedly of increasing importance in social and legal decision-making systems” (p. 245). Discussions of safety and risk figure prominently in dementia care research and present particular challenges in relation to freedom, personal choice and autonomy.
(Torrington, 2007). Parker (2001) warns that efforts to support social practices that affirm personhood are in danger in the context of an increasingly risk-averse culture led by a growing bureaucracy.

Dementia has been called the “disease of the century” (Leibing, 2006, p. 250). Of the various forms of dementia, AD has received by far the most media and public attention, and its notoriety has been shaped by overwhelmingly pessimistic depictions of older adults and the impact of dementia on the individual and their families. It is this reality that has led people with the disease, their families, as well as researchers and practitioners, to critically assess the current conception of AD and to bring attention to its foundation in the prevalent ageism of post-industrial societies. This work helps researchers to understand the powerful negative impact of the biomedical model on the illness experience of AD and dementia more generally.

**Transforming LTRC**

*The Role of Personhood*

Questions of the “essential ingredients of a person” (McLean, 2007b. p. 40) have long been debated by bioethicists and philosophers and are prevalent in the gerontological literature on dementia. In the realm of dementia studies, responses to this question have serious implications for understanding how dementia is constructed and managed in society. The prevalent narrative of dementia prioritizes cognitive function/ability and suggests that once diagnosed, the individual ceases to exist as a person. Given that as of 2010, more than 35.6 million people worldwide live with a
dementia with projections of 115.4 million by 2050, there is an urgent need to positively impact the master narrative of dementia (Alzheimer’s Disease International, 2010).

In these discussions, the scholarly work of the late Tom Kitwood continues to be highly influential. Kitwood brought the concept of personhood to the field of dementia studies and it is with his work that thinking about personhood in dementia is most closely associated (Brooker, 2004). Kitwood’s (1994/2007; 1997) social-psychological theory of personhood, which is central to person-centred care (PCC), was formulated to address what he perceived as the deficiencies that exist in conventional approaches to dementia care. Much of the impetus for a research on personhood comes from his recognition that, in the literature and in practice, there was little recognition of the subjectivity of the person with dementia. Kitwood’s work helped spark the “personhood movement” that emerged in the 1980s and took root in the 1990s in reaction to the extraordinarily pessimistic view of dementia that dominated the field of dementia care studies at the time (Leibing, 2006, p. 254). Since the 1990s, there has been a large body of research that grapples with Kitwood’s philosophical and practical approach to supporting the well-being of people with dementia, particularly those living in institutional settings.

Leibing (2006) suggests that personhood is raised as an issue for forms of human life or particular human beings, such as fetuses or for some people with a disability because they are unable to speak on their own behalf. Definitions of personhood can generally be divided into two categories: 1) the belief that personhood relates to an individual’s possession of specific capacities, or 2) that personhood is socially based and relates to a human being’s position within a moral community (Baldwin, Capstick, Phinney, Purves, O’Connor & Chaudhury, 2007). When Kitwood was developing his
theory, the former understanding of personhood was dominant. However, to the extent that Kitwood’s work confronted a biomedical equation of individual capacity (cognitive ability) and with the person (Baldwin et al., 2007), it set out to counter the dominant capacity-based view with a more socially grounded understanding of personhood. The “turn to personhood” (Leibing, 2006) and interest in therapeutic and relational importance of the care context went against the legacy of the Enlightenment and challenged the influence of philosophers Descartes and Locke, among others, who set the foundations for modern individualism in a prevalent mind and body split, i.e., the separation of cognitive and biological functions in which the former (thinking or the mind) are granted superiority (Hughes et al., 2006; Kontos, 2004; Matthews, 2006; McLean, 2007b; O’Connor et al., 2007).

The dominance of a capacity-based view might be seen as the source of much of the bleakness that surrounds diagnosis and care practice as it is rooted in neuropathology and Western medicine, with its preoccupation with treatment and cure (Herskovits, 1995). A diagnosis of dementia is considered to be synonymous with a reduction in the capacity to make decisions that sets the individuals apart from society: through diagnosis, “the brain and mind act as a source of difference” (Naue & Kroll, 2008, p. 26). When one loses the ability to reason, one loses the self—or so this dominant outlook has conditioned us to believe. The assumed loss of self is perpetuated through the workings of a medical model that locates “symptoms” in, for example, changes in an individual’s personality, behaviours, along with subjective complaints, and low scores on cognitive tests. It is a product of the “neuropathology of the disease” (Sabat, 2006, p. 287). In our society, individual memory might be considered the greatest requirement or evidence of
the self. An assumed loss of self has been noted as the most horrifying understanding of dementia (Aquilina & Hughes, 2006; Bastings, 2003; Crisp, 1999; de Medeiros, 2005; Herskovits, 1995).

**The Role of Person-Centred Care**

Since the late 1980s or early 1990s, the literature reveals that researchers and practitioners alike have increasingly sought alternatives to traditional biomedical care models in the form of person-centred care. This imperative has contributed to the spread of PCC models that emphasize both a more positive conceptualization of dementia and the importance of social processes, such as the impact of the creation of a positive social milieu on health, well being and quality of life in the LTRC context. Although Kitwood’s (1997) emphasis was chiefly based on the psychological domain of care, the promotion of personhood as the principal aim of his conception of PCC extended to interpersonal, social aspects of care (Baldwin & Capstick, 2007b). “We are social beings, and the greater part of most people’s lives takes place in relation to collectives of some kind” (Kitwood, 1990/2007, p. 275). Persons with dementia exist in a network of relationships that are created and maintained through interactions with others. In his words, personhood is “bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, 1997, p. 8). Challenging a prevalent “neuropsychiatric model of dementia,” Kitwood offers a “dialectical explanatory model of dementia” that shifts the focus solely from disease process to the interplay of brain disease with psychosocial factors (Kitwood, 1997; Downs, Clare, & Mackenzie, 2006, p. 245). Dementia is a neurological impairment, the experience of which is greatly influenced by one’s psychosocial environment. The view that dementia is manifested through a
dialectical process, that it is socially constructed, broadens the focus to include not only persons with dementia but also to carers (as well as all others with whom the person interacts). As Gilmour and Brannelly (2010) suggest, attending to personhood also involves a change in status for the carer away from “an anonymous, interchangeable manager of behaviour” to consideration of a carer “as a reflexive developed individual” (p. 242). This emphasis on interpersonal relations rather than disease processes obliges carers to reconsider their role.

Traditional care that tends to focus on rationality serves to undermine personhood by ignoring the fundamental human need for social connection and desire to be treated as a unique, complex individual. Traditional care often produces a state of what Kitwood (1997) refers to as ill-being in the person with dementia. The diagnosis and subsequent medicalization of individuals too often places those with dementia in a process/system that undermines their social being or personhood (Kitwood, 1997; Lyman, 1989; Sabat & Harré, 1992). Kitwood (1997, 1998/2007) is careful to point out that, although elements of care practice can serve to undermine personhood and even accelerate dementia, personhood-detracting care is not necessarily done with malicious intent by carers. Rather, poor care practice is often embedded in and perpetuated by a given organization or care culture, through particular beliefs, values and behaviour patterns. In this schema, a carer becomes acculturated to ways of caring with the result that what once might have seemed inappropriate or misguided to a person, over time becomes the natural, assumed way of doing things. In this light, a care culture operates as a system of taken-for-granted components of care practice. Kitwood (1997) referred to personhood detracting elements of practice, commonly found in formal settings, as evidence of an organization’s
“malignant social psychology” (MSP) (Kitwood & Bredin, 1992), which he operationalized through Dementia Care Mapping (to be developed in Chapter 4).

Kitwood’s thinking about PCC encourages a departure from task-oriented, custodial care that prioritizes “bed-and-body work” (Gubrium, 1975/1997) and movement toward a set of practices referred to as “positive person work” (Kitwood, 1997, p. 89). Linking the personhood of residents, their families, and care staff, these practices can be understood as opposite to MSP practices. It is through the recognition of the network of social relations experienced by the person with dementia, in addition to personal histories and preferences that carers might better understand how in their work they might either add to, or forestall, the progression of dementia. The value of this perspective for carers is that despite the absence of a cure for dementia, there is still much that can be done to improve the quality of life for people with dementia and the overall culture of care. Research on PCC suggests that carers can work to forestall or eliminate a premature social death for persons with dementia (Brannelly, 2011; Leibing, 2006).

**Culture Change Models**

Although PCC is recognized to be difficult to achieve in practice (Brooker, 2004; Dewing, 2008), the influence of person-centred orientation over the last 20 years has been considerable and has been used to support what has been called a “nursing home culture-change movement” (Rahman & Schnelle, 2008). Dawn Brooker’s (2004) statement that in the United Kingdom, PCC has become synonymous with or a “short-hand phrase” (Brooker, 2007, p. 15) for a good quality of care illustrates the growing popularity of PCC to address public and professional concern for more appropriate, humane care for LTRC populations. In 2012, this perhaps now not-so-new direction has
produced a wealth of scholarship and opened up previously unrecognized possibilities for
understandings of the subjective experience of dementia and for care practice.

Efforts to promote person-centred practice have taken several forms; although
there is no agreed upon definition of PCC, nor consensus in the literature regarding
specific components of PCC, many of these approaches that claim to be culture change
models share the same tenets and guidelines. With its basis in PCC, culture change is
complex and dynamic in nature, and has been described as:

The process of moving away from a traditional nursing home model, a system that
is unintentionally designed to foster dependence, [toward] a regenerative or
resident-focused model that increases the residents’ autonomy and sense of
control. It is seen as a continual process of growth and development and requires
systematic change at the individual and organizational levels. (Brawley, as cited
in Fazio, 2008, p. 158)

Examples of these models in Canada and the U.S. include the Eden Alternative (Thomas,
1996), and later The Green House Project (Thomas, 2003), The Pioneer Network (Fazio,
2008; Lechner, 2003) and Gentlecare (Jones, 2009). The Eden approach—one of the best
known and a key influence on my research site—maintains that boredom, loneliness, and
helplessness are at the core of the suffering experienced by “Elders” in LTRC (Eden
Alternative, 2007). William Thomas (1996), creator of this model, describe these “three
plagues” of institutional life as the outcome of a focus on medical treatment rather than
on “care,” or life. The Green House Project—also founded by William Thomas (2003) is
fundamentally different from other models that function within existing institutions
through its aim to transform institutional care from the ground up by abolishing “the
institution,” offering in addition to a focus on the human habitat of Eden, smaller living situations with greater resident contact, technological advances for charting and economic benefits through better management than current nursing home care.

Gentlecare is designed to offer “a prosthetic life care system” designed to meet the needs of “clients” with dementia (Jones, 2009, [www.Gentlecare.com/whatis.html](http://www.Gentlecare.com/whatis.html)) and The Pioneer Network ([http://www.pioneernetwork.net](http://www.pioneernetwork.net)) stresses interpersonal relationships and community (Fazio, 2008).

**Applying Theory in Practice**

The literature identifies key challenges for the application of PCC theory in care practice. In this section, I review the research that identifies the practical and conceptual limitations of PCC. Within these discussions, the need for specialized skills staff training and questions of adequate staffing levels to accommodate PCC principles and to support residents’ quality of life emerge as significant issues that impede implementation.

Although personhood and PCC as conceived by Kitwood has been at the vanguard of dementia research and transformations of dementia care, his work and that of his followers has been critiqued. More recent considerations of PCC acknowledge the transformational role this emphasis has in the field, but suggest that conceptually it has important limitations. In a comprehensive analysis, O’Connor and her colleagues (2007) stress the “intuitive appeal” of personhood, highlighting a lack of research into key dimensions (subjective experiences, immediate interactional environment and broader socio-cultural context) that would help link personhood theory with practice. Dewing (2004) also connects the challenge of applying theory in practice and contends that nurses
have yet to fully comprehend “personhood” as a concept. Dewing argues that this confusion is a hurdle in PCC practice. For similar reasons, McLean (2007b) warns against the “uncritical acceptance of person-oriented approaches” (p. 36). Part of McLean’s concern relates to questions of process and a failure of research to examine how and under what conditions PCC is most likely to benefit resident populations. Nolan, Davies and Brown (2006) assert that it is current interpretations of PCC that are problematic, rather than its initial intent (by Kitwood, Brooker and others), now “lost in common usage” (p. 48).

The quest to facilitate turning person-focused philosophies of care into person-centred practice is the focus of a significant amount of research in the field. Several studies identify the complexity of PCC itself as a primary hurdle to implementation and see this as a tremendous challenge faced by an organization (and thus, staff) to effectively carry out PCC (Aberdeen, Leggat, Barraclough, 2010). Innes (2009) points out that Kitwood’s vision for PCC practice “places huge demands” on carers: “Carers paid and unpaid, are often expected to perform physically strenuous, often ‘dirty’ work, while engaging in a positive manner with the emotional needs and demands of the individual they are caring for” (p. 49). The suggestion here is that PCC requires carers to be highly skilled in areas that extend beyond those of traditional front line care, which in turn requires organizations to attend to the unique needs of carers to deliver PCC and to facilitate appropriate responses to meet the unique needs of residents with dementia (Hughes, Bagley, Reilly, Burns, Challis, 2008).

To further explore the challenges of applying PCC theory in practice, I consider research on communication and dementia care that has emerged as instrumental in the
quest to humanize care. Specifically, I examine research on communication skills training and the use of biography to facilitate meaningful social interactions between staff and residents and more generally to support PCC practice.

**Communication Skills Training in Person-Centred Dementia Care**

The need for specialized staff training and ways to foster effective communication during care, more specifically, have received considerable attention. Kitwood’s vision for the transformation of a care culture promotes the need for staff education focused on specialized communication skills toward relational care (1993/2007), yet this aspect of his work was not fully articulated by the time of his death (Baldwin & Capstick, 2007b).

It is through our communication with others that we often convey respect, dignity and connection.

Research is developing in this area. A recent study by Savundranayagam, Ryan, Anas and Orange (2007) is an example of research that draws on the concept of personhood to examine communications (verbal and non-verbal) between staff and residents as a key aspect of foregrounding personhood within institutional care. These researchers found that “personhood-based” language that entails simplified and repeated language (instead of complex language) has a positive impact on staff interactions with residents, changing perceptions of both: they suggest the benefits of targeted communication training for carers (p. 58). Adams and Gardiner’s (2005) study focuses on the issue of communication techniques and social practices within care triads. This study examines communication processes (verbal and bodily expressions) that supports the involvement of the person with dementia and which contributes to his or her ill/well-being, aiming to lessen “disabling dementia communication” (Adams & Gardiner, 2005,
These researchers, and others, stress the need for innovative educational approaches that stress critical thinking around dementia care practice to empower carers to have a voice in the day-to-day care of residents (Ingersoll-Dayton, Schroepfe, Pryce & Waarala, 2003). Aberdeen and colleagues (2010) suggest the value and need for this type of training in relation to staff understandings of, for example, challenging behaviours associated with dementia (to be developed below). However, these researchers also recognize that the expectation that staff have specialized dementia knowledge “does not reflect the reality of the workplace” whereby staff are already burdened with documentation (to insure funding) requirements that do not necessarily reflect the demands of the job (Aberdeen et al., 2010, p. 144).

Burgio and colleagues (2001) also explore communication skills training to improve care. These researchers employed a communication-memory book training intervention and found that nursing assistants who had received communication skills training talked more and used more positive statements during care routines than those staff that had not receive this specialized training. Another key finding in this study was that these positive social interactions did not necessitate the investment of more staff time; rather, they used the time they had during their normal routine in a way that was personhood supporting. This study’s focus on the use of the memory book to aid communication between staff and residents is part of a large body of research that is focused on the use of resident’s biographical information to contribute to more personalized care and ultimately to achieve more balanced dementia care.
**Resident Biography**

The potential of biography to contribute to good dementia care has been identified in a significant number of gerontological studies. A focus on biography in dementia care literatures might be seen as a response, in part, to the neurodegenerative effects of dementia which results in a person with the disease experiencing increasing difficulty composing and sharing life stories (Baldwin, 2005; Gillett 2002). Biography is key to achieving PCC: Kitwood (1997) advises that, “having a sense of continuity with the past, and hence a ‘narrative,’ a story to present to others” (p. 83) is a collaborative effort: “to some extent identity is conferred by others, as they convey to the person subtle messages…” (p. 84). Similarly, Baldwin (2005) advocates that others must help in the co-construction of a meaningful and positive narrative for persons with dementia. When we begin to have difficulties with recall and word finding or with organizing and relating our experiences in intelligible ways, we require the participation of others (i.e., staff) to help tell our stories. According to Ryan and Schindel Martin (2011), the story of the person with dementia is an important means to sustain the self, while also sharing important aspects of his or her personal identity with others. The social nature of biography is a key aspect of biographical approaches to dementia care.

Despite the organizational and institutional difficulties raised by it, research has found a variety of positive outcomes associated with the use of a biographical approach—particularly around increasing the participation of family in residents’ care. Because these approaches draw on the personal expertise that families and/or significant others share with residents, they provide a means to involve friends and relatives in the care process (Gibson, 2005). The involvement of family in LTRC has been identified as a
missing ingredient in traditional models and is seen as vital to achieving optimal, individualized, dementia care (Reid et al., 2007).

Research has also shown how agitation and the display of other so-called dementia behaviours have decreased in settings that use biography. This is important because the dominance of the medical model in consideration of dementia-related behaviours means that alternative considerations have typically been sidelined or dismissed altogether. Graneheim and Jansson (2006) point out that it is critical to incorporate residents’ personal histories into understanding challenging behaviours within institutional settings. With personal histories in mind, carers might then interpret residents’ “disturbing behaviour” as a “way persons with dementia express their story and maintain their self” (Graneheim & Jansson, 2006, p. 1397).

This capability is connected with other demonstrated abilities of biography to help mediate the negative impact of institutionalization by; personalizing care, promoting relationships, and by helping staff to re-interpret challenging behaviours and thereby offer non-pharmacological alternatives in dementia care (Beach & Kramer, 1999; Kolanowski & Rule, 2001; Paterniti, 2003; Thompson, 2011). Biography has also been shown to facilitate staff-resident communications, inform care plans, and create opportunities for staff to support the identity of persons with dementia (Chaudhury, 2002a, 2002b, 2008; Dobbs, Eckert, Rubinstein, Keimig, Clark, Frankowski, & Zimmerman, 2008; Gibson, 1994, 2005; Hagens, Beaman, & Ryan, 2003; McKeown, Clarke, Ingleton, Ryan, Pepper, 2010; Ryan, Clark & Spadafora, 2005). Other related practice implications identified in the literature include a more hopeful outlook on living with dementia, increased involvement of the resident in his or her care, and the potential
for staff empowerment through creative engagement and interaction with persons with
dementia, and an overall decrease in residents’ social isolation (Allen-Burge, Stevens, &
Burgio, 1999; Brodaty, Draper, & Low, 2003; Clarke, Hanson, & Ross, 2003; Cohen-
Mansfield, 2000; Heliker, 1999).

The goal of biographical approaches is to enable carers to translate residents’ life
stories into care interactions (Moos & Björn, 2006). Biographical approaches include the
use of personal narratives, memory boxes, autobiography, life story, and life history. The
majority of these approaches is reminiscence-based and focuses on the use of tangible,
concrete records of residents’ life histories. Research on biography reveals that
biographical approaches to dementia care show great promise in their ability to facilitate
a fundamental shift in how care is given, received, and shared in the context of LTRC.
However, this research also shows that to be successful, staff should be given the time
and space to support residents’ identities and need to be trained to work with residents to
make biographical materials meaningful.

Barnes and Brannelly (2008) suggest the value of narrative to enable
personalized, equitable care, and Baldwin’s (2008) concept of “narrative space” describes
how care settings might foreground residents’ identities as “narrative beings” through the
use of their personal stories in everyday practice. Baldwin (2008) suggests that this
“narrative space”— a nexus of “personal, interpersonal and the institutional/structural”
(Baldwin, 2008, p. 224) aspects of care—is important to empowering persons with
dementia. Carers help move the marginalized person with dementia forward, supporting
her/his identity and social inclusion through “citizenship as practice” (Baldwin, 2008, p.
224). Yet, although meaningful communication has been identified as vital to an optimal
quality of residential care (Beach & Kramer, 1999), the literature on specialized training and the innovative education needed to enhance person-centred approaches, for example in the use of biography, illustrates the severe challenges that exist in LTRC to achieve this end.

Innes (2009) makes an important point when she states that the growing use of migrant (international) workers to care for older people in Western countries creates challenges in practice. Innes, and others, have pointed to language (and literacy) barriers that may exist between residents and direct carers, which negatively impact the ability for meaningful (verbal) interactions in care. With respect to biography, this issue presents opportunities in research to develop means to share vital biographical information in diverse ways, beyond solely text-based accounts and verbal interactions, of particular relevance in dementia care. Findings from my Master’s thesis (Kelson, 2006) identified the value of using personal photographs in a visual presentation of residents’ life stories to impart residents’ biographical details to care staff. Increasingly, technological, multi-media approaches are used as tools for life story work; video terminals, iPads and mobile phones for example, lend themselves well as alternate formats for the collection and sharing of biography (Cohene, Baecker & Marziali, 2005; Thompson, 2011). To promote person-centred practice, ways to support staff to engage with residents through meaningful communication and relationship is fundamental. These applications have the potential to provide carers from diverse socio-cultural backgrounds, who might have a range of comfort levels with the dominant language, an important means to foster their inclusivity in the lives of residents.
Challenges to Culture Change in LTRC

Research on staffing levels, quality of care, and the quest to achieve the best possible quality of life (QOL) for people living in long-term care represent key areas of practice that challenge an organization to transform practice. As this section will illustrate, what actually constitutes a good quality of life in LTRC has been hard to define and for persons with dementia in particular, is not well understood (Moyle et al., 2007).

Staffing Levels and Quality of Care

A considerable amount of research in LTRC focuses on the relationship between staff time and quality of care and the issues that surround these concerns. Understaffing in Canada, like in many other Western nations, is epidemic (Banerjee et al., 2008). This is a significant challenge to improving dementia care, because, as McGregor and colleagues (2006) found, there is a strong relationship between adequate staffing levels and better care in British Columbia LTRC facilities. Staffing levels represent a critical challenge, as the quality of residential care is dependent on front-line workers, such as healthcare assistants or care aides, the people who provide the majority of care (Smith, Kerse & Parsons, 2005).

Kitwood’s (1997) research addressed the necessity of a supportive organization to set the tone and provide the material resources necessary to enable a culture of care to deliver PCC. Kitwood (1997) speculated on the quality of care that exists in settings where the staffing levels are good and its relationship to good care. Far from current ratios, Kitwood envisioned the equivalent of one carer per three or four residents. Interestingly, he suggests practice situations where although the working conditions might reflect this optimal ratio, there was still evidence of less than optimal care, such as
superficial social interactions. This observation lends support to Kane’s (2004) assertion, that “levels of staffing, expressed as bodies per residents, may not tell the whole story” (p. 253).

However, in general, research points to a link between optimal care and higher staffing levels (Canadian Union of Public Employees, 2009; McGregor, Tate, Ronald, McGrail, Cox, Berta & Broemeling, 2010; Schnelle, Simmons, Harrington, Cadogan, Garcia, Bates-Jensen, 2004). For example, in a widely cited U. S. study by Schnelle and colleagues (2004), they recommend that 4.5 hours of direct care, per resident, per day is required in order to improve the quality of LTRC. This goal differs greatly from the most recent Ombudsperson Report (British Columbia. Office of the Ombudsperson, 2012) that states that care facilities in the province are working toward 3.36 hours of direct care hours for residents. There is also another component to this equation that relates to which care roles are best able to improve care and the life of residents. Specifically, is care improved through an increase in nursing staff, leisure staff, social workers, or medical staff? There is also debate in the literature about whether an optimal number of direct care hours exists that all facilities should work toward to ensure quality care for the increasingly complex care needs of resident populations. In short, fundamental questions in this area query which staff roles have the greatest potential to improve care and whether or not an optimal ratio of staff to residents exists.

Murphy’s (2006) research sheds light on these questions. Whereas many studies advocate increased direct nursing care, Murphy (2006) found that all members of the care team (e.g. RN, LPN, RCA) contributed, in unique and shared ways, to the quality of residential care. Murphy also asserts that minimum levels of staffing are needed to avoid
a number of adverse care outcomes (e.g. physical restraints, pressure ulcers). Zhang and Grabowski (2004) study of U. S. reforms in over 5, 000-nursing homes add further insight to this discussion. These researchers identified a significant increase in staffing levels from 1987 to 1993. However, they also found that this increase was associated with better outcomes in only those facilities that were the most undersupplied and had the least favourable ratios. This study then reveals that the relationship between increased nursing staff and improved quality of care is not necessarily clear-cut.

Despite agreeing with the general rule that “more is better,” Kane (2004) maintains that many studies are challenged to identify a significant correlation between more staff and improved care (p. 252), given the inconsistencies in, for example, staffing data and units of analyses used across studies. Moreover, Kane (2004) supports the broadening of measures of staffing beyond nursing to include other carers, like activity staff. Reid and Chappell (2003) offer a rare study that explores staff-resident ratios in relation not to nursing staff, but rather, to activity staff in special care units. They found that even a modest increase in the ratio resulted in appreciable benefits to SCU residents in terms of decreased agitation and improved quality of life.

When considering the notion of person-centred care, an additional problem emerges: staffing levels are often determined in relation to custodial aspects of LTRC. McLean’s (2007b) and others’ research on PCC suggest the need to consider staffing levels not just in relation to instrumental tasks, but also with respect to care philosophies. McLean’s (2007b) study compares care in a traditional and non-traditional setting and she details the internal and external barriers to quality dementia care. Namely, she identified internal caring practices that suggested the “superiority of person-preserving
care” over instrumental approaches to support residents’ personhood (McLean, 2007b, p. 221). She notes that care of the person requires that carers possess the attributes of patience, flexibility, and other skills needed to engage in relationship-based care. McLean (2007b), Banerjee and colleagues (2008), and others describe this type of care as labour-intensive. Citing the potential resource limitations that impede transformations in practice, Lopez (2006a) contends that at present we don’t “really know how, or whether, culture change allows nursing homes to transform nursing home care with existing levels of staffing” (p. 59). This literature suggests that the ability for staff to care for the “person” depends not only on the skills of the individual carer, but on organizational support and factors beyond the level of the organization—to external forces—historical, political cultural, economic (McLean, 2007b).

**Defining Quality of Life**

What the studies of quality of care and staffing issues discussed above do not capture is the vital yet nebulous dimension of LTRC known as quality of life. Research on QOL in LTRC reveals the challenge of definition. This absence of an agreed upon definition, or broad definition of quality of life, is considered to have a detrimental impact on assessment (Kane, Kling, Bershadsky, Kane, Giles, Degenholtz, Liu, & Cutler, 2003). It seems that although QOL is increasingly considered as an outcome in dementia research and practice, and has been used to guide economic decisions in residential care (Moyle et al., 2007), it remains an intangible and elusive concept (Crespo, de Quirós, Gómez, & Hornillos, 2011).

Evaluations of quality of life began with the work of Lawton (1994, 1997) who used a combination of subjective and objective measures in the following interrelated
areas: psychological well-being, behavioural competence, the physical environment and care provision, and perceived quality of life (cited in Torrington, 2007). Although there is a general consensus that LTRC must promote a good QOL for residents (Kane et al., 2003), there is comparatively little literature focused on QOL in LTRC (Moyle et al., 2011). There is also a dearth of research focused on how residents’ diversity and social locations impact his or her experiences of life in LTRC. Reasons for these gaps in knowledge include the challenges that exist in defining, measuring, and studying QOL in residential care (Kane, 2003).

One evaluation tool that has been altered in the quest to better assess QOL in LTRC is the RAI/MDS. First iterated in 1988 (Rahman & Applebaum, 2009), the Minimum Data Set (MDS) is a standardized resident assessment instrument (RAI) that has become ubiquitous in the industry; it is used in nearly every U. S. nursing home (Rahman & Applebaum, 2009) and many Canadian LTRC facilities (Kontos, Miller, & Mitchell, 2009), including the research site of this study. The intention of the RAI/MDS is to facilitate improved, individualized care and is designed to operationalize residents’ care plans. However, this standardized assessment tool has been critiqued for its inability to capture residents’ personal preferences (Kane et al., 2003; Kontos et al., 2009). The latest version (3.0, in 2010) inserts a number of changes designed to address such critiques. For example, in an attempt to better include residents in their own care the latest version requires that staff conduct resident interviews (with scripted questions) (Rahman & Applebaum, 2009). Still, while there are many strengths of the RAI/MDS tool around physical care and the implementation of best-practices across sites, major criticism of this tool’s most recent version has been its failure to include important QOL
psychosocial domains (such as dignity, enjoyment, or comfort) and the limited attention it pays to residents’ sense of security and the importance of personal relationships (Rahman & Applebaum, 2009), or whether staff honour residents’ rights (Koren, 2010). In PCC, these domains are considered vital in order to evaluate a resident’s social needs and tap into ways to ensure an optimal quality of life.

**Expanding Concepts of Personhood and PCC—Conceptual Issues to Date**

In recent years, research on the conceptual limitations of personhood and PCC theory that may impede culture change has increased because of the observed difficulties in application of PCC principles on the ground. In this section, I look at these conceptual limitations in relation to embodiment, the physical environment, agency, and the contributions of relationship-centred approaches.

**Embodiment**

There is increasing interest in individuals’ bodily engagement in the world—or embodiment—as a vital aspect of personhood (Kontos, 2004; Kontos & Naglie, 2007; Phinney & Chesla, 2003). This perspective might be seen as a response to the Western (Cartesian) separation of mind and body whereby the experience of dementia is “explicitly not a bodily one” (Phinney & Chesla, 2003, p. 285). Twigg (2004) makes the point that feminists (characterized by a variety of debates and positions) have begun to take issue with recent accounts of the body, age and identity that fail to capture the whole person (i.e., mind and body). Specifically, Twigg (2004) observes a “revival of Cartesian dualism” (p. 62) in representations of dementia in some postmodern research that emphasizes discourse and culture and effectively rejects physiology. She sites Kontos
(1999), Gibson (2000), and others as challenging these old dualisms and instead advancing the notion that the body is produced and reproduced through the dialectical relationship with the self. Therefore, the quest to support personhood in dementia care and humanize practice requires acknowledgement of the body as inextricably linked to the self.

An appreciation in practice for a greater recognition of the ways that residents are embodied and engage in the world through a range of bodily acts and modes of communication is vital to person-centred practice. Kontos & Naglie (2007) suggest that “shared bodily experiences,” such as a resident and carer walking arm-in-arm or sharing a hug, opens the door to personal connections between residents and staff and contributes to more compassionate care. In terms of practice, a failure to appreciate embodiment as a component of personhood perpetuates cognitive understandings of personhood and unfairly disadvantages persons with dementia by failing to recognize the many ways of communication that are not language-based.

**The Physical Environment**

Another conceptual limitation addressed in the literature relates to the omission in PCC to include considerations of the impact of the built or physical environment on the well-being of the person with dementia. This is an area that is under-researched in dementia studies (Barnes, McKee, Parker, Morgan, Torrington, & Tregenza, 2002; Cutler & Kane, 2003). However, consideration of the built environment in the interests of culture change is vital, because “the person experiences living with dementia” within a particular context or experience “they do not experience themselves and the physical and social environments as separate, rather each is in relationship with the other” (Davis,
Research that has focused on physical environment has tended to focus on the use of design to reduce or eliminate “problem behaviours” rather than as a resource to support personhood (O’Connor et al., 2007). There are some exceptions to this: Thomas’s (1996) Eden Alternative touches on the reciprocal relationship between the physical environment and the psychosocial health of residents, and staff, when it suggests that, in addition to changes in care philosophy, organizational policies and practice, changes in physical design are important to support the development and maintenance of intimate relationships; changes in the built environment are conceived of as an “antidote to loneliness.” Examples of these changes that already contribute to quality of life in Eden include small kitchens that are accessible day and night to residents (versus an institutional kitchen) as well as the addition of “spa” rooms (versus shower room). Unfortunately, the evidence-based data supporting the value of physical environment on personhood is sparse.

An exciting contribution to PCC research in the area of built environment is the recent addition of a physical environmental component to the Dementia Care Mapping (DCM) observational tool (Chaudhury, Cooke & Frazee, in press). Although recognized internationally for its ability to assess residents’ quality of life and the extent to which a person-centred approach has been implemented in a care setting, the most recent (8th) edition of DCM (Brooker & Surr, 2005) was still unable to assess residents’ behaviour, mood and engagement in relation to the physical and environmental features. Currently in the pilot stage, the addition of the physical component to the DCM tool incorporates Lawton’s work on quality of life as it relates to environmental situations (Cooke & Chaudhury, 2012). This work underscores the interplay between social and physical
environments on the well/ill-being of persons with dementia and adds to the few empirical studies that demonstrate how and in what ways a PCC approach actually improves residents’ well-being. Importantly, it also adds to the small number of research tools that exist, as Edvardsson & Innes (2010) point out, to allow research to move beyond evaluations based on proxies to direct measures of person-centred practice.

**Agency**

A small number of researchers have explored subjectivity, the preservation of self (Sabat & Harré, 1992; Sabat, 2002a, 2002b) or “the subjective experience of personhood” (Nowell, Thornton, Simpson, 2011). This research begins to draw attention to the notion of agency. This research is vital to this study because its focus on agency challenges normative assumptions of disease, age and cognitive impairment. It relates to the proposition that the person with dementia is an active agent who continues to engage in the preservation of his or her selfhood (Downs, et al., 2006; Beard, 2004; O’Connor et al., 2007; Bartlett & O’Connor, 2007). Research indicates that persons with dementia employ a variety of strategies in an effort, for example, to sustain a connection with their self-identities (O’Connor et al., 2007): faced with dementia “People are resilient and tailor techniques when necessary” (Beard, 2004, p. 426). Phinney (2008) points out that persons with dementia might embrace health promoting behaviours, such as changing their diet or level of physical activity, working harder at tasks, or perhaps asking for assistance from others to help them remain involved in activities they find meaningful. Other research in this area looks at how persons with dementia employ narrative techniques and communication strategies to remain engaged in the preservation of self (Adams & Gardiner, 2005; Baldwin, 2005; Chaudhury, 2008; Paterniti, 2003; Sabat,
While most of the research on subjective experience and agency has focused on early stage dementia, McCollgan’s (2005) research highlights the retention of agency even in the context of long-term care. Specifically, this researcher found that residents engaged in various acts of resistance (i.e. self-preservation) as they made an effort to exercise autonomy and choice. These included arranging furniture in common areas in particular ways (against the desires of staff) in order to accommodate their need for quiet reflection and to escape the gaze, and feigning sleep in order to detach from the routinized environment of the nursing home. While not focused explicitly within a long-term care setting, a recent study by Sabat and Lee (2011) on social cognition and the possibility of friendship in persons with dementia pointed to the ways in which people in a moderate “stage” of dementia independently initiated social interactions that defied what their neuropsychological test scores would suggest were possible. These researchers found that people diagnosed with dementia were able to “recognize and honor one another’s needs, supported one another in caring, tender ways, sought to be helpful to one another and found ways of expressing acceptance of one another” (p. 323). In an enlightening twist, they concluded that these individuals with dementia demonstrated supportive behaviours that could be described as in keeping with Kitwood’s notion of Positive Person Work—his objective for personhood-supporting staff-resident interactions.

**Relationship-Centred Care**

While early research and literature focused on personhood and PCC, more recently, recognizing the importance of relationship, specifically, the understanding that quality care must occur in the context of a relationship (Brooker, 2008; Kitwood,
the use of language has shifted and models based on ‘relationship-centred care’ (RCC) are now emerging. Critics of policy decisions that have resulted in the widespread adoption of person-centred models claim that they are misguided because they focus to a large extent on the individual, subjective experience of dementia (McCormack, 2004; Nolan et al., 2006; Nolan et al., 2004; Nolan, Ryan, Enderby, Reid, 2002). In part, this criticism is leveled at Kitwood’s contention that personhood is the basis for PCC. McCormack (2004) points out that while the importance of relationship to PCC is undisputable, that it represents but one component of personhood (with context, place, and self being others) and concludes therefore that “relationship-centred care” is a more inclusive term (p. 33). Nolan and his colleagues (2002, 2004, 2006; Ryan, Nolan, Reid, Enderby, 2008) are perhaps most influential in the realm of relationship-centred approaches and suggest that the conceptual shortcomings of PCC is rooted in its inability to fully account for the “interdependencies and reciprocities that underpin caring relationships” (2002, p. 203). These researchers acknowledge the centrality of a respect for personhood to transform care, but call for a less individualistic understanding in dementia care that values interdependencies in the care context (Brown Wilson, Davies, & Nolan, 2009). They further assert that PCC not only fails to improve institutional care, but suggest it “perpetuates” poor standards of care by failing to consider the impact of both interpersonal processes and “intrapersonal experiences of giving and receiving care” (Nolan et al., 2004, p. 49).

They propose the Senses Framework (Ryan et al., 2008) as a “more exciting and appropriate vision” (Nolan et al., 2006, p. 48). In addition to the person with dementia/formal carer dynamic, a key aspect of broadening the vision of care (beyond
PCC) as they describe it in this model, is the recognition of the network of relationships in which family plays a vital role in residents’ quality of life (Nolan et al., 2002; Nolan et al., 2004). A hurdle to the implementation of RCC, as with PCC, surrounds the challenge of reaching theoretical consensus in order to facilitate implementation in practice. In particular, it is difficult to pinpoint the conditions that actually produce and maintain positive relationships in care (Nolan et al., 2004).

Some research suggests that instead of focusing on the differences between PCC and RCC, the two models can work in tandem with one another (O’Connor, 2008). For example, Dewing (2008) counters some of these critiques with claims that popular analyses of Kitwood’s work have oversimplified it and devalued the philosophical roots of PCC. Dewing (2008) contends that the philosophical underpinnings of personhood as relationship-focused, his promotion of Buber’s “I-Thou” mode of relating, and of PCC practice as “moral concern for others” has been marginalized (p. 11). This focus on intersubjectivity between carer and person dependent on the care, in this case the resident, marks a key site of interest and research on how best to transform formal dementia care. It also raises important philosophical concerns around the limits of humanist conceptions of subjectivity and individual agency. Adams (2008) takes the comparison a step further and not only warns against a polarization of approaches, he draws attention to continued limitations of both, suggesting that while both PCC and relationship-centred approaches have contributed valuable ideas to dementia care, both approaches suffer from a lack of focus on socio-economic and political factors that shape the experience of care for persons with dementia, their families, and carers.
Ethics in Person-Centred Care

Of all the troubles that come to human beings, dementia is one of the most difficult to face, and one that presents some of the most intractable ethical problems. (Kitwood, 1998/2007, p. 155)

As discussed, ethically-based relationships figure prominently in considerations of the transformation of organizational culture in LTRC. Foundational to personhood and PCC is the contention that persons with dementia, like those without, possess intrinsic worth and value as human beings (Kitwood, 1997; Post, 1995). While this may seem self-evident, older people are often objectified, even within the field of gerontology, which risks turning older adults and persons with dementia into objects of study in what has become a largely problem-based approach to aging (Herkovits, 1996; Katz, 1996; Twigg, 2004). Gerontological research informs societal discourses, theory, and practice and when we are not careful there is a danger of contributing to the dehumanization of persons with dementia through the way we understand the complex concerns that impact aging and the elderly. Leedham & Hendricks (2006) point out that gerontology has contributed to a normalization of aging as a period of physical decline and social withdrawal. Recent research argues for the need to counter a tendency to exclude individuals from the “‘personhood club’” (Kitwood, 1997, p. 9) through consideration of the multifaceted nature of agency and ethical relations at play in research and practice.

Ethics in dementia care is key to person-centred approaches because, as Hughes and Baldwin (2006) point out, “much ordinary care involves an ethical component, even if it is not recognized as such” (p. 9). A focus on ethics in dementia care challenges the dominant medical model and its continued influence on how dementia is perceived and
“managed” in the day-to-day lives of residents. The next few paragraphs discuss research on ethical relations and their ability to support good dementia care. They also look at challenges to the implementation of ethical ideals in practice.

I/Thou and I/It Modes of Relating

Kitwood (1997), Post (1995, 2006), Hughes and Baldwin (2006), and others draw on philosophical discussions of interpersonal, ethical relations to help theorize approaches to transforming dementia care practice. For example, Martin Buber’s (1878-1965) notion of the I-Thou/I-It relationship has influenced gerontological research by providing a vital theoretical perspective for considerations of personhood, relationship, and ethics of care. Kitwood (1997) suggests that Buber’s work is important to seeing personhood in relational terms and offering important connections through discourses based on “transcendental, ethical and social-psychological” accounts of personhood (Kitwood, 1997, p. 11). Kitwood’s conception of personhood is rooted in Buber’s notion of the “I-Thou” relationship: “a symbiotic relationship between caregivers and people living with dementia” (Baldwin et al., 2007, p. 177). Kitwood (1997) suggests that conventional practice is based on and perpetuates I-It encounters, which entails negative outcomes for both residents and staff. Without a true meeting, one based on openness, tenderness and acceptance, which is how Kitwood (1997) characterizes an I-Thou encounter, there is no true intimacy or relationship created between two active subjects (Buber, 1970/1996). Instead, these I-It ways of interacting negate the personhood of both parties and focus primarily on the tasks of care and the goal of getting the job done, and the receiving of care.
Intentional and Non-Intentional Modes of Relating

Research on ethical care practice has also looked to the philosophical writings of Emmanuel Levinas (1906-1995) to help understand the relationships that exist, or not, in care encounters (Greenwood, 2007; Greenwood, Loewenthal, & Rose, 2001; Lavoie, De Koninck, & Blondeau, 2006). Levinas’ thinking about intersubjective relationships offers an important contribution to our understanding of socially responsible care practice. It is significant to note that Levinas (1958/2009) critiques Buber’s work on modes of relating. For instance, Levinas challenges Buber’s emphasis on a level of reciprocity that is contained in an I-Thou mode of relating: “The position of the I … is not interchangeable with that of the Thou” (1958/2009, p. 72). Levinas recognizes the asymmetrical obligations that exist in relations between oneself and the “Other” (Hand, 1989/2009). This distinction has great relevance to understandings of dementia care practice. Rather than considering a relationship (between resident and carer) as being based on mutual acceptance, which is what Buber does (Greenwood et al., 2001), Levinas (1984/2009) stresses that our sense of responsibility toward the other arises from a responsibility for the Other. It entails a moral obligation. Lavoie and colleagues (2006) develop the philosophy of Levinas vis-à-vis an ontology of care, specifically, nursing care. These researchers assert that Levinas’ emphasis on the face of the Other, and the responsibility for others that occurs in practice when “face to face with another person, especially one in need…compels one to do something for the other” (Lavoie et al., 2006, p. 228). With reference to dementia care, McLean (2007a) argues that relational care is essential in the prevention of or resistance to more conventional instrumental care practices. To McLean,
dementia care is a “moral enterprise because it addresses fundamental human vulnerabilities, both of care receivers and their caregivers” (2007a, p. 369).

Adding further complexity to Buber’s modes of relating, Levinas discusses the concept of the “non-intentional” (Levinas, 1984/2009). Whereas Buber’s I-Thou necessitates conscious consideration of the other, Levinas interprets this awareness as an obstacle to a true meeting (Levinas, 1958/2009). He offers instead the concept of the non-intentional, which Levinas describes as generated in a caring relationship in the moments prior to a conscious, or intentional, understanding of the other person, or the person as “other.” In dementia care, this view might help staff counter the dominance of biomedical evaluations of the person in care. A carer’s ability to be open to the value of non-intentional “pre-understandings” (Greenwood, 2007, p. 223), Levinas suggests, allows carers to overcome the powerful influence of labeling or social stigmatization. As Greenwood (2007) writes, “a person’s internalized view of another person can inhibit the possibility of allowing real individuality to emerge in a relationship” (p. 224). Goslinga and Frank (2007) note the relevance of the non-intentional to ethnographic research and suggest that Levinas’ basis for ethical (face-to-face) engagement with Others is applicable to the creation of new, ethically-based epistemologies. Specifically, they discuss how anthropology might be advanced through fieldwork that engages with “subjects,” relinquishes the power of the researcher, and thereby, as Levinas suggests, produces research encounters and ultimately knowledge that is “dynamic, tentative, relational” (Goslinga & Frank, 2007, p. xvii).

Emphasis on the individual carer’s responsibility to ethically interact with residents, while important, has been criticized for failing to acknowledge the broader
collective responsibility within the care environment in which the care interaction takes place (Baldwin & Capstick, 2007b). In other words, while individual responsibility to engage with a resident, and others, as persons (“Thou”) is important, it does not acknowledge a larger social context and the organizational-level imperative to create spaces (personal and relational) as an intrinsic part of the philosophy of care. More specifically, while training is important, on its own, it is insufficient (Banerjee et al., 2008). There is evidence that the practice of ethical care becomes an undue burden for individual carers when it fails to take into account structural hurdles to PCC (O’Connor et al., 2007). As an extension of this point, the omission of a complex understanding of the institutional contexts in which ethical care takes place might also be seen as a major hurdle in the translation of PCC theory to practice.

**Activity, Social Inclusion, and Exclusion in LTRC**

The ability of a LTRC facility to transform from a traditional, medically-based mode of care to one that also attends to the everyday needs and preferences of the “person” is often discussed in the literature through exploration of the social environment. These discussions centre on issues of social inclusion or social exclusion and their respective influence on residents’ well-being. Activity figures prominently in these discussions.

The literature on care facilities shows that high levels of boredom and social monotony endured by residents define life in “the nursing home” (Ice, 2002). Goffman’s (1961/1991) description of institutional life and its soul-destroying impact on the individual remain influential in research devoted to improving daily life in LTRC which continue to evoke images of confinement and a loss of control and privacy. Foucault’s
(1977/1995) historical analysis of disciplinary mechanisms and power relations highlights the impact of social isolation on the person experiencing it, likening it to modern-day punishment. Whereas, historically, punishment was enacted through corporeal means (namely torture), more recently societies engage in non-corporeal forms of punishment through imprisonment and the associated deprivation of one’s rights and liberty: “it is no longer the body” [that suffers], it must be the soul” (Foucault 1977/1995, p. 16).

Foucault develops a model of exclusion that is based on his analysis of how society in the Middle Ages dealt with individuals and the social practices of deciding who might be labeled abnormal. Individuals who were deemed abnormal, as in the case of lepers, were cast out “into a vague, external world beyond the town walls, beyond the limits of the community” (Foucault, 1999/2004, p. 43). The result of this marginalization, this “spatial partitioning” of groups of individuals, was that “two masses were constituted, each foreign to the other” (Foucault, 1999/2004, p. 43).

This Othering is echoed in Davies’ (2003) depiction of the nursing home in BC in the late 19th century. Davies (2003) contends that the early nursing home in British Columbia should be understood as part of “a larger project whereby the state used formal, public institutions to separate the needy and deviant from the rest of society” (p. 55). In this way, residents were physically and culturally removed, “shut out of public discourse and community perceptions of where and how the aged lived” (Davies, 2003, p. 57). Of course this outcome was not overtly stated in the official literature; rather it was socially practiced. For example, it was determined that nursing homes should reside on the
outskirts of the city so that residents would be removed from the noise and activity of the city into more peaceful and pastoral surroundings (Davies, 2003).

Factors in Social Exclusion

Within the institution itself, research indicates that there is a further social partitioning. This social division is expressed both materially and ideologically. LTRC research shows that internal divisions are connected to the institutional use of space; in particular, special care units (SCUs). Foucault’s (1967/1984) concept of non-places or “heterotopias” highlights a material practice of separation relevant to the SCU. Heterotopias are described as forgotten or marginalized places that are reserved for particular individuals who are either in crisis or whose behaviour is labeled deviant. Within LTRC, the SCU might be seen as a perfect example of a heterotopia. Constructed during the 1970’s, SCUs are a response to the perceived problem of an increase in residents with severe cognitive impairment and the desire to isolate residents who were deemed “behaviourally difficult” from the “normal” resident population (McLean, 2007b, p. 61). Examples of so-called challenging behaviours include aggression, agitation, wandering, hitting and yelling (McLean, 2007b; Morgan & Stewart, 1997; Rosen, T., Lachs, M. S., Bharucha, A. J., Stevens, S. M., Teresi, J. A., Nebres, F., & Pillemer, K., 2008).

Although SCUs were developed to provide a prosthetic environment (both socially and physically) to prevent these identified challenging behaviours when a resident is deemed likely to benefit from supportive physical and social setting, research on the effectiveness of the SCU is inconclusive (Kovach & Henschel, 1996; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). It seems that despite the greater
financial investment in SCUs, research identifies few if any benefits (for example, in functional abilities or cognition) to residents of an SCU (Grunier, Lapane, Miller & Mor, 2008; Reimer et al., 2004). In addition, the spatial partitioning of residents with dementia in the SCU context has been questioned in light of statistics that indicate that up to 70 percent of the resident profile in long-term care setting have some cognitive impairment, yet do not receive specialized care (Calkins, 2001).

How social inclusion/exclusion in LTRC operates at an ideological level is evident in Kitwood’s (1997) description of a care culture that exhibits a malignant social psychology (MSP). Kitwood (1997) highlights the divisions that exist within organizations marked by a MSP where differences between “us” (care staff) and “them” (residents) come to be taken-for-granted ways of being, with negative implications for both. The care staff has been shown to be highly significant in residents’ social inclusion or exclusion. Bruce’s (2004) research on social exclusion (and inclusion) develops this point through what is described as an “inverse care law,” which stipulates that, “as dementia becomes more severe, the likelihood of appropriate care for emotional, physical, occupational, spiritual and social needs decrease” (p. 126). Bruce attributes this “law” to a disparity between the demands of the job and the skills of the staff. Namely, a lack of specialized skills or the staff’s inability to communicate with residents with cognitive impairment creates a pessimistic outlook for the residents and impacts the staff’s perceived ability to make a difference in residents’ lives. Bruce (2004) found that of all the possible contributors to social inclusion, staff views were the most influential. To ameliorate this, this researcher maintains it is imperative to counteract (common
sense-based) negative opinions or stereotypical ideas within organizations with more positive resident-focused understandings.

Person-centred approaches seek to address the negative outcomes of spatial partitioning, which are material and ideological and which are linked to the social exclusion of residents of long-term care from the wider community and from the social life within a care setting. Studies indicate that a growing number of residents have some degree of dementia and that this segment of the population is at increased risk for social isolation. Nevertheless, dementia does not diminish a person’s need for social inclusion (Kitwood, 1997); it might even produce a greater need for human connections (Brooker, Woolley, & Lee, 2007). Kitwood’s (1997) vision for culture change includes recognition of (social) inclusion as one of the main psychological needs of persons with dementia. Similarly, Thomas’s (1996) Eden Alternative describes boredom, loneliness and isolation as endemic to traditional care and sets to eradicate these problems through his Edenization of a care setting. This model however is not specific to dementia and research evidence on its usefulness is inconclusive (Coleman, Looney, O’Brien, Ziegler, Pastorino, 2002). Despite increased attention to dignity and quality of life, and the trend toward improved décor to create more “home-like” settings, social isolation and impoverished lives for residents are still evident (Bruce, 2004; Calkins, 2001).

**Successful Aging and Activity**

The association between well-being and activity has deep roots in social gerontology (Litwin & Shiovitz-Ezra, 2006). Early on, Erikson’s (1950) psychosocial developmental stages, canonical in aging studies, established that as individuals reach the last stage of life they encounter increased tension or conflict between the dichotomous
categories of ego integrity versus despair. According to this model, when a person reaches old age (the 8th stage), a natural withdrawal from productivity occurs and the person enters either a reflective state where one is either proud of the life they have led (ego integrity) or is dissatisfied (despair) (Brown, Lowis, 2003). In contrast, activity theory connects sustained engagement in life to well-being and, ultimately, to “successful aging” (Litwin & Shiovitz-Ezra, 2006). The promotion of the concept of successful aging in gerontology served to counter earlier theories that focus on the disengagement of the older adult whereby individuals inevitably relinquishes his or her roles and responsibilities, an idea that was presumed to be a natural part of growing older (Minkler & Fadem, 2002).

While there are many arguments for and against Erikson’s model and other considerations of activity in old age, these tend to produce a false binary, as Katz (2000) points out, around activity and inactivity (reflection). Activity in old age is a complex issue. The notion of activity in old age as a “universal ‘good’” (Katz, 2000, p. 136) and that inactivity is generally “bad” remains pervasive in gerontology. Katz (2000) links the social construction of activity in the field to a political economy where “most gerontological and policy discourses pose activity as the ‘positive’ against which the ‘negative’ forces of dependency, illness, and loneliness are arrayed” (p. 147).

In the 1980s, Rowe and Kahn popularized understanding of the dichotomy between positive aging and negative aging through the concept of successful aging, which was described as an absence of disease (Minkler & Fadem, 2002). In contrast to the loss and decline paradigm that had dominated gerontology, the notion of successful aging provided an important alternative perspective in the field; it highlighted the
importance of lifestyle and allowed researchers and carers to identify the complex factors that put some people at risk for disease and disability (Minkler & Fadem, 2002). Although this perspective has served to challenge negative conceptualizations of old age, it too is problematic (Minkler & Fadem, 2002). As Leedham and Henricks (2006) point out, discussions of successful aging with its emphasis on the importance of individual responsibility for a healthy lifestyle fails to account for the social, structural influences that impact how a person ages. These researchers suggest that the concept of successful aging is problematic because it represents the Eurocentric values of a predominantly white, male middle class, and therefore excludes diverse voices of those disenfranchised across divisions of gender, class, race, age or ability.

With respect to dementia and LTRC, the tendency to position people in relation to successful aging has created particular conceptualizations of “success” and its usual corollary, unsuccessful aging. Minkler and Fadem (2002) address the limitations of this concept through their application of the successful-aging paradigm to people with disabilities, a group that by definition are excluded from considerations of successful aging. Katz attributes this binary to “neoliberal antiwelfarist agendas” which are interested in the “uncritical promotion of positive activity,” while also problematizing “older bodies and lives as dependency prone and ‘at risk’” (2000, p. 14). In his equation, dementia by its nature is appraised as unsuccessful aging.

In relation to dementia, views on successful aging are particularly contentious, largely because of the normalization of definitions of the concept, which serve to obscure “the possibility of aging creatively in the face of disease and disability” (Leedham & Henricks, 2006, p. 37). Von Faber and van der Geest’s (2010) research in this area led
them to conclude that “success” in aging should be reconfigured, largely because it is understood differently, or defined differently, by the people experiencing it than by those evaluating from the outside—family members or health professionals.

**Activity, Well-Being, and Dementia in LTRC**

Katz (2009) explains how despite the pervasive use of activity in gerontology, there is no agreed upon definition of activity. He also contends that the construction of activity in terms of success and the valuing of an active body in old age allows for a host of professionals (nurses, occupational therapists, activity staff) to exist: “activity expands the social terrain upon which gerontologists and related professionals who work with the elderly can intervene” (Katz, 2009, p. 126). Important to my study is Katz’s contention that within institutional settings, a particular type of “busy” body is sought after, namely, one that can be managed. In LTRC, this process is evident in the management of residents’ bodies by a host of staff who oversee and assess residents engagement both in relation to daily self-care activities like bathing and getting dressed (known as Activities of Daily Living) as well as in structured, leisure-type activities. In many residential settings, this engagement is monitored through the Resident Assessment Instrument (RAI) (Mor, Bronco, Fleishman, Hawes, Phillips, Morris & Fries, 1995). However, challenges in assessment occur when markers of engagement and activity differ from the behaviours and preferences of individuals in care, for example, in cases where a resident prefers to engage in a solitary or contemplative activity (like prayer or meditation) or a more passive, less structured everyday activity (like making tea or sweeping the floor). These less valued activities challenge conceptions of “activity” and correspondingly the way we evaluate individuals’ engagement in the social life of a care setting.
Research on activity in LTRC and the well-being of persons with dementia can be broadly divided into two interrelated areas: 1) the therapeutic use of activity, namely, to prevent dementia-related behaviours, and 2) the role of (meaningful) activity to support personhood and the overall well-being of persons with dementia.

1) Therapeutic Activity: Meeting the Needs of the Person. As suggested, activity in the LTRC context is usually discussed in terms of structured, recreational activities that possess therapeutic value. The objective of therapeutic recreation has been described as maximizing “functional capabilities of clients and to help in the rehabilitation of the ‘total person’ by alleviating humanistic problems related to psychological and physical disability (Greenblatt, 1988 as cited in Ice, 2002, p. 347). Examples of activities common in LTRC include arts and crafts, music, bingo, baking, and current events.

Research suggests that activity is an important part of residents’ quality of life including ameliorating many of the challenges of institutional life. For example, Schreiner, Yamamoto and Shiotani’s (2005) found that for half the residents in their study, the only time they demonstrated happiness was during recreation time. This study and others identified residents’ access to and engagement in activity as integral to the prevention of negative or problem behaviours commonly experienced in LTRC, especially in persons with dementia (Cohen-Mansfield, Marx, Thein & Dakheel-Ali, 2010; Kovach & Henschel, 1996; Schreiner et al., 2005).

Literature on activity in LTRC has traditionally considered activity in relation to the prevention and management of challenging behaviours. More recently, however, research is beginning to highlight the importance of understanding individual actions as attempts to communicate a range of personal needs or desires (Cohen-Mansfield, 2000;
Granheim & Jansson, 2006; McLean, 2007b); these understandings counteract the biomedical pathologization of the individual (Dupuis, Wiersma, Loiselle, 2012) and a narrow focus on treating symptoms (i.e. the behaviours) through chemical and/or physical restraints. This research suggests a need to consider a range of factors in residents’ social, psychological and physical environment.

The ability of LTRC to support residents’ continued involvement in daily life by meeting their social (psychological) needs is a key aspect of the discourse on culture change. It is reasoned that LTRC prioritizes residents’ physical and medical needs, while failing to meet residents’ social needs (Hancock, Woods, Challis, & Orrell, 2006). Participation in structured activities and group events has been shown to help residents meet their social needs, and in so doing, to improve their quality of life. This in turn reduces negative behaviour and might be seen to improve an individual’s health and well-being. Dewing’s (2006) research on the behaviour of wandering illustrates the impact of biomedical understandings of walking as well as the potential of the social context of care to support residents engagement and overall mind/body well-being through activity. Dewing (2006) suggests the importance of reconceptualizing wandering, changing it from a problem to an activity. This endeavour requires, in part, taking steps to enable people to walk, rather than striving to prevent it. It might be that walking was a part of the person’s life and an expression of self, or perhaps, walking is a way of coping with stress or even an adaptive response to a person’s “premorbid” state (Song & Algase, 2008). Increasingly, with the proliferation of person-centred theory, negative behaviours are represented less in terms of a natural outcome of a disease process, and more as an
expressions of unmet needs—or in the case of wandering, possibly “a natural activity” (Dewing, 2006, p. 247).

Kitwood’s work is fundamental to such a shift in understanding activity and well-being. Kitwood (1997) includes “occupation” as one of the five psychological needs of persons with dementia. To him, occupation “means to be involved in the process of life in a way that is personally significant, and which draws on the person’s abilities and powers” (p. 83). For some residents, those who are more capable and able to express themselves vocally, their agency to participate in their own care is clearer. But, this type of agency is harder to identify in people with more advanced dementia and, as Kitwood (1997) suggests, it becomes the responsibility of the institution to support residents’ through respect for “occupation” of both the individual but also to support carers’ creativity and knowledge development so that they can fulfill the needs of the person with dementia. For example, Harmer and Orrell (2008) point out the importance of staff sensitivity and skills training to produce the necessary physical and social environment adaptations to support the involvement of persons with dementia. These skills might also be considered in relation to Kitwood’s description of empowering residents through enabling, facilitating, and collaborating care practices (Brooker & Surr, 2005).

2) Personhood Support: Finding the Meaning in Activity. A small body of research looks at the need to recognize the importance of personally meaningful activity as a potential resource for fostering or eroding personhood (Phinney, Chaudhury, & O’Connor, 2007). Commonly, research on PCC considers carers’ ability to support occupation and contribute to the well-being of residents is grounded in an understanding of a person’s past and their personal preferences. It is through the identification of what is
meaningful to the individual that carers might maximize the likelihood of residents’ participation in life’s processes and their overall well-being and quality of life. The literature suggests a general consensus on the importance of meaningful activity to support personhood and the well-being of individuals across the dementia journey.

Until now, research on activity for persons with dementia has largely focused on activity that takes place in formal care settings (Phinney et al., 2007). In this body of literature there is scant attention paid to what makes activities meaningful to persons with dementia and what their activity preferences are (Harmer & Orrell, 2008; Leone, Piano, Deudon, Alain, Wargnier, Balard, Soriano, Malléa, Robert, Dechamps, 2012; Menne, Johnson, Whitlach, & Schwartz, 2012; Phinney et al., 2007). There is also little known about how best to translate this knowledge toward the social inclusion of the most marginalized residents (Knight & Mellor, 2007).

One study that makes an important contribution to this field is by Harmer and Orrell (2008). They found that the quality of the experience of activity was pivotal, rather than the type of activity. This research also established that what made activities meaningful to residents was related to values and beliefs that were affiliated with past roles, as well as past interests and routines. Enjoyment was also a vital ingredient to engage residents. Those activities that reinforced a sense of identity and belonging were also meaningful. In short, activities in which residents found meaning were those that fulfilled their psychological and social needs. Other researchers have also identified personally meaningful stimuli, such as past work roles, to engage residents with dementia (Cohen-Mansfield, Marx, et al., 2010, 2010b; Kovach & Henschel, 1996; Popham & Orrell, 2012). In a study on meaning and activity in community dwelling persons with
dementia, Phinney and her colleagues (2007) point out that participants’ engagement in a range of activities (household chores, leisure and recreation, and work-related activities) facilitated a sense of connectivity and belonging, while also helping individuals to retain their autonomy and sense of self, despite their dementia diagnosis.

If the involvement of people with dementia in activity hinges on a sense of continuity, and activities that are based on a person’s past preferences are particularly effective to the engagement of persons with dementia, the importance of being able to access and use this information to inform care plans and practices emerges. Hence, the link between the use of biography in care and occupation, discussed earlier in this chapter, seem clearly inter-related. However, the research suggests that despite the identified, multi-faceted benefits of activity, only rarely is activity considered an essential part of a resident’s care plan rather than something that is supplementary, diversional or recreational (Palmer, 2010). This is a vital area of research for development, because as Brooker (2008) states, the provision of activities and opportunities grounded in the needs of residents rather than the needs of the institution is essential to making a life worth living in a care facility.

**Chapter Summary**

Much of the research addressed here illustrates a central impasse that exists between theory and practice, and between research and day-to-day life in LTRC. It highlights the difficulties that emerge in the process of translating largely humanistic, ethics-based theories of personhood, person-centredness, and relational care into practice. Despite the relatively abundant research on the conceptual strengths of PCC, there remains a scarcity of empirical research on the benefits of such an approach to care
practice, and there are few research tools in use that elucidate the association between PCC and a better quality of life (Edvardsson, Winbalk, & Sandman, 2008; McCormack, 2004; Nolan et al., 2004; Packer, 2000). Noted for its complex and multidimensional nature (McCormack, Dewing, Breslin, Coyne-Nevin, Kennedy, Manning, Peelo-Kilroe & Slater, 2010), PCC still requires understandings of what organizational factors facilitate or hinder implementation and practice (Epp, 2003; Innes, 2009).

This chapter outlines the complex landscape of dementia care and LTRC more generally, in which the needs of the institution and the broader socio-political context of care intersect and often conflict with the needs of the “person” in care, i.e., those needs apart from, but not mutually exclusive of, biomedical needs. Accordingly, this study endeavours to add critical empirical research to this evolving field. Although a considerable amount of research has explored the importance of relationships in care, and biography shows great potential in this area, only recently have social structural issues in LTRC that challenge the resources of staff skills, time, money, and organizational support been considered. This tension is also evident in the literature on activity in dementia. There is general consensus in the research on the importance of social inclusion to the well-being of residents and staff, but what is less clear from the research is how to support this end in light of projected profiles of residents who are generally frailer, sicker and living with more advanced dementia. There needs to be more research on meaningful activity for residents, especially those with dementia, in order to design care plans to represent the desires and preferences of the person and, in so doing, to better meet residents’ social needs for pleasure, occupation, and overall well-being.
CHAPTER 3:
CONCEPTUAL FRAMEWORK

In this chapter, I describe the conceptual framework guiding this study. This ethnography was conducted under the epistemological influence of critical social theory. No single approach provides a sufficient conceptual foundation for this ethnography. Instead, I draw on a range of perspectives that link social theory with social aspects of aging in order to respond to my research objectives: critical, Foucauldian and feminist gerontology. In combination, these critical perspectives inform this study. Each provides an important lens for considering the interface between personal and interpersonal, organizational, and structural levels, under the assumption that understanding a culture of care requires recognizing the importance of how all three levels work to shape daily life for the people who live and work in the care setting.

In this chapter, I outline the overarching framework for this study, beginning with critical gerontology and then going back to the foundational works of Foucault and feminist gerontology. My use of these different critical approaches strives to build on Tom Kitwood’s seminal work in the area of dementia, personhood, and person-centred care that provides structure to my consideration of the relational aspects of care and the process of culture change underway at Cedar Grove.

Critical Gerontology

Critical gerontology is an area of scholarship that has gained momentum over the last 20 years, challenging many of the tenets and theories of mainstream social gerontology. To Ray (2008), “critical gerontology serves the necessary role of casting a
critical eye on society and the field of gerontology itself” (p. 97). Minkler (1996) articulates two paths that have emerged simultaneously in critical gerontology: a political economy path and a humanistic path. In general, the political economy path considers issues of aging in social structural terms and focuses on issues of power, social location, and inequality as fundamental to consideration of the aging process. The humanistic path, as Minkler describes it, explores broad questions of meaning in the lives of older people. Although these paths are distinct, Minkler contends that there are also times when they intersect. Similarly, Katz (1996, 2009) critiques gerontology for a narrow focus, and he suggests that there is a need for a blurring of disciplinary boundaries to create stronger ties with the humanities and to make greater use of reflexive methodologies and a radical political engagement. The absence of critical analyses in mainstream social gerontology, Baars and colleagues (2006) suggest, has limited understanding of social processes that shape the life course and old age as well as alternative perspectives on conceptions on old age. Katz (2009) describes critical gerontology as “a vibrant subfield blending humanities and social science ideas to challenge the instrumentalism of mainstream gerontology and broaden aging studies beyond biomedical models” (p. 85).

Critical gerontology foregrounds concern for social justice and equality in order to effect positive change, for example, in how aging is socially constructed, studied, and experienced. The desire to transform research and practice hinges on knowledge production and mobilization that strives to challenge taken-for-granted assumptions of positivism. The ontological and epistemological challenges that come to light in critical, feminist and Foucauldian gerontology focus on “truth” claims and the separation of subject-object relations. All critique the possibility of value-free, objective analyses by
demonstrating how power relations that are socially and historically grounded mediate academic research (Guba & Lincoln, 2005; Kincheloe & McLaren, 2005; Strega, 2005).

Thus, the integration of a critical perspective within gerontology problematizes foundational theories in studies of aging. Powell & Longino (2002) argue that postmodern ideas have helped move theories of social gerontology to include more productive or optimistic images of old age. The value of critical gerontology to this exploration of LTRC is that it helps to expose experiences of care and daily life (for residents and staff) as more than features of individual experience. This perspective compels us to question why things are done particular ways and how they became accepted as the norm (Bartlett & O’Connor, 2010). A critical perspective also helps to foreground a contextualized, multi-dimensional understanding of life in LTRC by examining how individuals are constructed within particular structures and contexts. It endeavours to recognize and promote understandings of the socio-political interconnections, synergies, and tensions that influence the provision of residential care.

**Foucauldian Gerontology**

Within critical gerontology, the work of philosopher Michel Foucault has been highly influential. In this study, his scholarly writings on power and knowledge, particularly as they converge around institutions, have been instrumental in my quest to contextualize and expose the social functions and organizational culture shaping the social space of LTRC and describing the roles and experiences of residents, their families, care staff and administrators. Foucault provides a wealth of scholarship that critical sociologists and gerontologists have taken up to theorize aging and the institutional lives of older adults (Brijnath, Manderson, 2008; Grenier & Leonard, 2006;
Katz, 1996; Powell & Biggs, 2000; Powell & Longino, 2002; Powell, Biggs, & Wahidin, 2006; Twigg, 2004; Wahidin & Powell, 2001). Mostly, widespread use of his theories and concepts, even as they relate to aging, has come out of social and cultural studies: Powell and Wahidin (2006) suggest that these theories and concepts have been under-theorized in aging studies. This represents a potentially important gap in knowledge. Culpitt (2006) suggests that Foucault’s analytic tools are valuable to the radical exploration of established politics and social policies relevant to aging. In this vein, Manias and Street (2000) employ what they call a “toolbox approach” in their research of nursing practice. This is consistent with Foucault’s own thinking on the potential utility of his scholarship for social inquiry:

All my books…are little toolboxes…if people want to open them, to use this sentence or that idea as a screwdriver or spanner to short-circuit, discredit or smash systems of power, including eventually those from which my books have emerged…so much the better. (Cited in Manias & Street, 2000, p. 50)

In the paragraphs below, I discuss the Foucauldian concepts that I have used as tools for understanding institutional care and how they helped build interpretation and shape analyses in this critical ethnography.

**Space and Power in LTRC.** Foucault’s representation of the Panopticon and the associated “gaze” has been widely applied to critical studies of biomedicine and the institutional care of older people. In *Discipline and Punish—The Birth of the Prison*, Foucault (1977/1995) refers to an architectural feature created in the late 18th century by Jeremy Bentham. An economist by trade, Bentham created the Panopticon as a means of enabling the social control of many prisoners by few guards. He accomplished this
through the physical design of prison. A “central tower” from which the guards might maintain constant surveillance of inmates’ cells that were organized in a circle around it functioned as an extremely powerful disciplinary mechanism. Not only did it serve the practical needs of the institution—allowing the guards to see prisoners—it also functioned “to induce in the inmate a state of conscious and permanent visibility that assures the automatic functioning of power” (Foucault, 1977/1995, p. 201). As Foucault (1977/1995) famously describes it, the Panopticon shows how “power has its principle not so much in a person as in a certain concerted distribution of bodies, surfaces, lights, gazes; in an arrangement whose internal mechanisms produce the relation in which individuals are caught up” (p. 202).

In the field of aging and dementia, the “gaze,” as Foucault identifies it, has come to take many forms. In gerontological literature, there are prevalent references to the “medical gaze,” “the clinical gaze,” the “gaze of youth,” a “cultural gaze,” and a “professional gaze.” Feminists add to this the notion of the “phallic gaze” (Heaton, 1999; Malacrida, 2005; Powell & Biggs, 2000, 2003; Twigg, 2004). In various ways, this work speaks to Foucault’s argument that the power of the gaze is dependent both on its “interiorization by, and devolution to, the objects of surveillance” (Heaton, 1999, p. 770). This means that counter to the belief that power is possessed by few and subjected on many, Foucault’s concept of the gaze illustrates the democratic nature of power.

This notion has provided an important lens in my research for understanding the ways in which residents not only feel the effects of the gaze from staff, but also internalize the gaze and project it onto others. The functioning of the gaze in this way helps to understand power in LTRC in diverse ways. For example, power is not seen to
be *strictly* top-down, or “uni-directional,” enforced by those at the top of the hierarchy (management) down to those at the bottom (residents). Rather, as Foucault and others have demonstrated, the effects of power flow and circulate in all directions, from top to bottom and side to side (Heaton, 1999). Bringing a Foucauldian lens to my analysis helped facilitate interpretations of the multidirectional flow of power and drew attention to the complexity and tensions surrounding individual behaviour.

When applied to LTRC at the organizational and structural level, this understanding illustrates how staff are subject to the gaze of residents, other staff, as well as management who, in turn, are subject to surveillance and power through licensing agents, policy makers, family members and the visiting public. Foucault’s treatment on the exercise of power reveals the ways in which people are not merely the victims of a powerful other, but rather active subjects who are capable of action and choice (Culpitt, 2006) and who in the process produce and reproduce various power dynamics.

**Discourse and Power in LTRC.** In *The Birth of the Clinic* (1963/2003), Foucault explores the origins and operation of the gaze and what he refers as discourse in relation to biomedicine. One of Foucault’s most important contributions to academic research is his notion of “discourse.” In general, discourse might be defined as a “set of possible statements about a given area,” and discourse “organizes and gives structure to the manner in which a particular topic, object, process is talked about” (Kress, 1985, p. 7, as cited in Cheek, 1999, p. 387). The gaze of modern medicine functions as a disciplinary mechanism within the nursing home, and as Foucault (1963/2003) describes it, is essential to the development of a medical discourse that began in the late 19th century when the doctor’s gaze made visible what until then had been invisible; it enabled one “to
see and to say” (p. xiii). For Foucault (1963/2003), what is said, i.e. the discourses at play in a particular context, allowed for the creation of the clinic or the hospital; it opened up a type of intense surveillance, which “establishes the individual in his irreducible quality” making it possible “to organize a rational language”(p. xv) around care of the body. This medical gaze then creates the possibility of a person being an object or a “case,” allowing medical discourse to produce diagnoses (to expose the “truth”) that in turn legitimizes a certain course of action (Chatterji, 1998; Malacrida, 2005).

For Foucault, knowledge produced through discourse is characterized by regulation and established parameters; “discursive practices maintain discourses that subsequently constitute power relations and knowledge” (Manias & Street, 2000, p. 52). The gaze and dominant discourses it produces function as instruments of government enacted through the work of the caring professions, such as nurses, “a powerful group” that “helps the state to govern at a distance” (Holmes & Gastaldo, 2002, p. 563).

In LTRC, dominant discourses governing care that determine delivery have traditionally been biomedical. Biomedical models construct aging as a problem that is characterized by decline, dependency and decay (Powell & Biggs, 2003). Because a biomedical lens underpins commonsense approaches in practice, alternative approaches compete to gain importance. In other words, recognizing that disease processes alone do not determine a person’s well-being in LTRC (Kitwood, 1997; Lyman, 1989), for people with dementia in particular, the continued dominance of a biomedical perspective is a source of potential exclusion (Brannelly, 2011; Innes, 2009; O’Connor et al., 2007; Bartlett & O’Connor, 2007, 2010).
In my study, I drew on this understanding to recognize the importance of shifting attention to discursive practices, culture members’ everyday talk, as well as official statements contained in organizational documents as a vital step for understandings of what helped and hindered culture change in the research site.

**Bio-power in LTRC.** Bio-power was used by Foucault to identify a form of authority that emerged in the 18th century whereby sovereign rule over subjects was replaced by the “administration of bodies”, specifically, the “subjugation of bodies and control of populations” (1978/1990, p. 140). This period of history saw the advent of state run clinics, schools, and universities, each exerting certain types of power over and through various members of society. Foucault highlights how whereas at one time in history, power over life and death emanated from the sovereign, with the advent of capitalism, the law operated to propagate power over life and preserve social order, in part, through the production of a “normalizing society” (1978/1990, p. 144).

In *Discipline and Punish—The Birth of The Prison*, Foucault (1977/1995) writes that,

> The judges of normality are present everywhere. We are in a society of the teacher-judge, the doctor-judge, the educator-judge, the ‘social worker’-judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to his body, his gestures, his behaviour, his aptitudes, his achievements. (p. 304)

To Foucault (1978/1990), the production of a “normalizing society,” which ultimately ensured the smooth functioning of the economy, describes how the lives of residents, no longer a part of the workforce or productive economy, are shaped through a kind of
process of normalization. Foucault referred to the combination of professional experts and the objects of power—in the case of my study, residents—as a kind of “carceral network” or “panoptic web.” In this network of power and knowledge, residents are subjected to surveillance and monitoring, which in turn allows them to be judged according to various measure of normality. It is important to recognize that, within the research process, the researcher adds to the disciplinary network with the additional power dynamic created by the social sciences and knowledge production. In the field, I considered myself part of this network whereby I produced knowledge via my position as a qualitative researcher-judge, an ethnographer-judge, and a Dementia Care Mapper-judge. I saw myself very much functioning within Foucault’s carceral network or panoptic web.

The Foucauldian conception of bio-power, power over bodies and the standards or norms created by way of disciplinary knowledge is foundational to this investigation; it helps to foreground the “rational administration” of LTRC institutions (McLean, 2007b, p. 111). Conceptually, attention to bio-power elucidates the normalizing forces in institutional-based dementia care and the study of aging in general, helping to locate the local administration of care and inquiry in wider social, economic and historical processes. It helps shed light on the legacy of the nursing home Davies (2003) identifies in her history of residential care in British Columbia, specifically, the extent to which “Old age homes have always been physical manifestations of social and culture attitudes toward the last phase of life” (p. 54).
Feminist Gerontology

Finally, I discuss how feminist perspectives provide an important critical lens for this study. Specifically, feminist insights and scholarship in the areas of knowledge production, ethics, carework and intersectionality have all contributed to my ability to shape the research questions posed in this ethnography and interpret emergent findings from my fieldwork.

By virtue of demographics, at least in the wealthiest countries, aging has been constructed in research and policy as predominantly a women’s issue (Graham & Stephenson, 2010; Ray, 1996). Carework is also primarily a women’s issue (Martin-Matthews, 2007; Twigg, 2004). Despite this situation, there is scant feminist research in the field of gerontology. Calasanti (2004a) notes that few gerontologists identify themselves and their work as feminist, which is perhaps surprising in light of the obvious overlaps between research devoted to aging, ageism, citizenship, social policy, and carework.

In feminist discussions of dementia and social justice, the work of Barnes and Brannelly (2008) and Bartlett and O’Connor (2010) offer important insights of great relevance to this study. These researchers stress both practical and political applications of a relational ethic of care in the context of dementia. Ethic of care principles, serve to challenge normative assumptions of dementia as an individual experience, putting forward the need to address the “interdependencies, connections and relational vulnerabilities” (Bartlett & O’Connor, 2010, p. 61) entailed in the dementia experience. Barnes and Brannelly (2008) also advance the value of an ethic of care as a shared value base from which to promote interdisciplinary communications vis-à-vis ethical decision-
making. Another important example of the implicit influence of feminist thinking on
dementia research is Dewing’s (2007) work on informed consent involving persons with
dementia in research. She too draws on a feminist ethic of care to broaden discussions
beyond cognition to include a focus on relationship, communication and affect as
important to the research consent process. Dewing’s work is instrumental in
demonstrating how feminist methodology might be used to look at the convergence of
power and knowledge in care research.

Although theorists argue that some strains of feminism and postmodernism\textsuperscript{1} are
incompatible, such as in more positivistic feminist approaches, the research that I draw
on in this study suggests that the similarities and differences in the philosophical and
epistemological underpinnings of both have provided fruitful discussions in critical
theory (Ramazanoglu & Holland, 2002). For example, Twigg’s (2004) research provides
a useful example of feminist gerontology that borrows from Foucault to explore the issue
of bathing in institutional settings. Theoretical discussion of the overlaps between
postmodernism and feminism have pushed feminist gerontologists to think creatively
about power and the production of knowledge through the taking apart of the foundations
of positivism: postmodernism deconstructs “knowledge, power and reality in order to
examine how various connections between them have been produced, and with what
effects” (Ramazanoglu & Holland, 2002, p. 86). In the area of social construction,
postmodern thought that is consistent with feminist thinking which challenges the

\textsuperscript{1} The literature on critical research offers many and sometimes conflicting definitions of postmodernism. To compound matters, it is often used interchangeably with poststructuralism. In this paper I deal with the work of Foucault, a key thinker for both postmodernists and poststructuralists. While, technically speaking, Foucault’s philosophical writings might be properly described as poststructuralist (Hammersley & Atkinson, 1995; Strega, 2005), his writing have become foundational to much postmodern cultural criticism.
assumed neutrality inherent in positivist knowledge production, foregrounding issues of representation through a focus on the questions of research rather than answers (Ray, 1996).

Because of important intersections between postmodern/post-structuralist and feminist thought there are a number of researchers whose work might be identified under the title postmodern feminist. These researchers draw on a critical lens, which includes recognizing gender as a social construct. For example, Twigg’s (2004) study highlights the gendered nature of carework, where caring and nurturing are assumed to come naturally to women, and correspondingly, how women are considered the natural choice to provide care for the bodies of residents (who are also predominantly women). Here, the concept of intersectionality helps to disrupt normalized assumptions around carework (both as “skilled” and “unskilled” labour) and to shed light on the power relations that circulate within care situations. In another example, O’Connor, Phinney and Hulko (2009) recognize how different social locations, including gender, inform the dementia experience in complex and contradictory ways.

In keeping with critical social theory, feminist gerontology “can be seen as part of a wider emancipatory project of developing epistemologies in the social sciences that challenge dominant perceptions by starting from the perspective of the lives of the marginalized and oppressed: in this case the old (Laws, 1995, as cited in Twigg, 2004). The acknowledgement in feminist gerontology that gender intersects with age, race, class, sexual orientation, and other markers of difference in ways that privileges some and oppresses others sheds light on the often gender-based, invisible relations that occur in
day-to-day life (Calasanti, 2004b). This understanding is also relevant to thinking about daily life in LTRC.

**Intersectionality.** The consideration of “the other” in postmodern thinking is closely linked to the concept of intersectionality. Within feminist research, intersectionality is seen to have the ability to address issues that conventional feminism is accused of obscuring—that is, the influence of multiple identities on women’s lives (Ramazanoglu & Holland, 2006; Davis, 2008). Interest in intersectionality has been attributed to attempts to come to terms with issues of race and racialization, and to address the failure of feminist researchers to acknowledge lived experience in a way that reflects “multiple subordinate locations as opposed to dominant or mixed locations” (McCall, 2005, p. 1780). Intersectionality has been called one of the most important theoretical contributions to women’s studies and other related fields of study (McCall, 2005). It fits well with critical ethnographic methodologies that are comfortable with the notion of multi-vocality and interpretive practices that strive to achieve thick description (McCall, 2005).

The popularity of intersectionality rests in its attempts to address a central concern of feminist methodology: the recognition of differences and multiple positionings of women across, for example, age, class, ethnicity, sexuality, and ability (Davis, 2008). Moreover, intersectionality is valuable in that it provides a means of “challenging the singularity, separateness, and wholeness of a wide range of social categories” (McCall, 2005, p. 1778). That is, it begins from the idea that an individual might occupy several social categories at the same time, with certain aspects of her position or identity emerging as relevant in relation to different contexts. More than an abstract concept,
intersectionality is valuable for understanding “the dialectical relationship between the personal and the political” (Hulko, 2009, p. 44). Intersectionality responds to the accusation that not all women can or should speak for all others, and it has gained attention and use in critical research.

There is considerable variability as to whether “intersectionality” is a concept, a paradigm, a theory, an approach, a lens, or something else (Davis, 2008; Hulko, 2009). In the literature, intersectionality is referred to as a concept, at other times, as a theory or a heuristic device. Sometimes, it is a research paradigm and sometimes a strategy for feminist analyses (Davis, 2008; McCall, 2005). Although she is resistant to demands for an agreed upon definition or for the need to set methodological guidelines around its use, Davis (2008) offers the following definition: “Intersectionality refers to the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power” (p. 68). Hulko (2009) points out the importance of moving beyond the typical focus on race, class, and gender to include age and disability, which are of particular significance to older women. Other’s highlight that positions cannot be understood as cumulative advantage or disadvantage, but rather positions can operate in tandem or tension with one another in complex and conflicting ways (O’Connor et al., 2009).

Rather than perceiving this conceptual uncertainty as a weakness or methodological obstacle in social research, McCall (2005), Dressel, Minkler, & Yan (1997), and others, assert that intersectionality might be seen as a concept that helps us understand how the social and cultural constructions of age shape and determine the
experience of growing old. This perspective has been instrumental in allowing me to frame understandings of individuals’ varied experiences of daily life, and the ways in which particular locations privileged some, and oppressed others.

**Changing Culture: The “Person” in Care**

My ability to grasp micro-level, personal and interpersonal relations in the culture under study was informed by personhood and person-centred care theory articulated primarily by Tom Kitwood and those researchers who followed in his footsteps. Kitwood (1997) considers as reductionist the belief that one’s experience of dementia is a product of neurological disease alone. His research led him to formulate strategies for the transformation of LTRC, where the “whole context needs radical improvement – through a change in the culture of care” (Kitwood, 1997, p. 42). Kitwood considered a positive social environment to be vital to the well-being of both residents and staff and considered exposing taken-for-granted aspects of care as vital to culture change. To Kitwood, dementia care is skilled work that has the potential to empower staff and residents, especially in contexts where there is proper attention to personhood. It seems to me that there are strong parallels between research conducted from a feminist standpoint, where there is an assumption of the “inseparability of politics and epistemology” (Ramazanoglu & Holland, 2002, p. 67), and person-centred research; both strive to incorporate the voices and experiences of systemically marginalized individuals in society.

As discussed above, Foucault’s (1999/2004) work on the power of language to construct experience sheds light on the production of social divisions between normal and abnormal, or between sane and mad. Kitwood’s (1997) descriptions point to similar divisions that define LTRC, where he saw a culture of care marked by a malignant social
psychology characterized by disparities between “us” (care staff) and “them” (residents). Goffman (1961/1991) details analogous divisions in his description of the “staff-inmate line” (p. 89). Developing these divisions in aging studies and practice, Graham (2010) cleverly considers that “‘them’ are ‘us’ in not so many years” (p. 186). Post (2006) advocates for the social inclusion of everyone in a moral community, irrespective of cognitive ability. He maintains, ‘the differences between ‘them’ with dementia, and ‘us’ without it are a matter of degree more than of kind” (p. 225). My awareness of an ever-present potential to other residents and of the power of social divisions was important to how I considered the culture of care I was studying. Just as vital was my attentiveness to care interactions that broke down these barriers by creating opportunities for personhood support, positive interpersonal relations, and better relational care.

To broaden the social context for Kitwood’s work, my research looked to recent gerontological discussions of Levinas, whose writings on intersubjective relationships might be applied to long-term care practice. Levinas (1958/2009) conceives of social interactions that occur between oneself and the Other as being (optimally) grounded in “asymmetrical obligations” (Hand, 1989/2009). Levinas (1963/2009) also describes the “non-intentional” as meetings between two people that are not based on “pre-understandings,” but rather, involve meeting a person where they are at in the moment, without preconceptions (Greenwood, 2007), thus radically reversing or challenging Buber’s I-Thou. Levinas’ critical approach to intersubjective relations and their grounding in a power differential are vital to this study and have helped to illuminate supportive care interactions as well as the overall care culture.
Summing up, this chapter outlines the various critical perspectives and person-centred theory that form the conceptual frame of this ethnographic study. In combination, these perspectives help to bring into relief multilevel issues in the care culture that produced and reproduced culture members’ experience of life in LTRC. This framework also reveals how each lens adds to a more holistic understanding of cultural practices as well as the influences of broader socio-political factors on the LTRC context. Finally, this framework helps to illuminate person-centred practices and the various challenges at all levels to the transformation of a culture of care.
CHAPTER 4:
RESEARCH DESIGN

The purpose of this investigation was to critically explore the impact of a person-centred care (PCC) philosophy on the daily life of residents and staff in an urban-based long-term residential care setting located in Western Canada (Cedar Grove). Through a qualitative ethnographic methodology, I present data generated through multiple methods and representing the perspectives of the various constituent groups that comprise the culture of care. Guided by critical social and gerontological theory, I examine how care is experienced at the personal, interpersonal, and organizational levels as well as the influence of wider socio-political-economic factors that shape culture members’ experiences of life and work in a Canadian LTRC setting. Given the identified gap between theory and practice in relation to person-centred care, this study seeks to add empirical data to understandings of the implementation of a person-focused philosophy at the level of practice in Canadian LTRC. My ultimate goal in this study is to positively impact the living conditions of residents, especially persons with dementia, as well as the working conditions of the people who care for them.

This chapter is divided into three main parts. I begin with a description of the study’s overall methodological approach: critical ethnography. This is followed by a section focused on data generation, which presents an account of negotiating entry to the research site through to the various strategies utilized for generating data. In the next section, I discuss how data generation methods are employed in relation to data analysis and interpretation, the ethical considerations raised by this study, and key limitations.
Methodology: Critical Ethnography

Ethnography is actively situated between powerful systems of meaning. It poses its questions at the boundaries of civilizations, cultures, races, and genders. Ethnography decodes and recodes, telling the grounds of collective order and diversity, inclusion and exclusion. It describes processes of innovation and structuration, and is itself part of these processes. (Clifford, 1986, p. 3)

The methodology of critical ethnography was used in this study in order to obtain a richly textured description and in-depth understanding of a long-term residential care facility undergoing organizational culture change. A prolonged period of fieldwork including the primary method of participant observation, both consistent with traditional ethnography, enabled me to examine social and cultural practices “where the group works” (Creswell, 2007). Critical ethnography, like traditional ethnography in which it is embedded (Thomas, 1993), seeks to describe and interpret patterns of behaviour, beliefs, interactions, and language of a culture-sharing group (Creswell, 2007). Creswell (2007) describes ethnography as both a process and an outcome that involves an extended period of (usually participant) observation and immersion of the researcher in the daily lives of the culture members. Although critical ethnography shares many of the same tenets as traditional ethnography, it adds an explicit political purpose (Thomas, 1993). Specifically, critical ethnography endeavours to expose how various social, political, and cultural forces construct reality (Strega, 2005). It questions inequalities of power associated with privilege, access, and wealth, and advocates the use of research for change (Patton, 2002). Like other critical methodologies, critical ethnography is interested in developing interpretative approaches that might help us to better understand
social life—how people find meaning in a particular setting—in order to create significant change.

Consistent with a critical approach, this study aims to challenge the status quo (Cook, 2005; Creswell, 2007) and to disrupt “taken-for-granted assumptions by bringing to light underlying operations of power and control” (Madison, 2005, p. 5). In so doing, this methodology allows the researcher (me) to gain insights into the various forms of domination and exploitation that have become “naturalized in everyday social life” (Kincheloe & McLaren, 2005). Thus, my investigation of LTRC had a transformative agenda (Hardcastle, Usher, & Holmes, 2006; Kincheloe & McLaren, 2005; Madison, 2005; Simon & Dippo, 1986; Thomas, 1993). As Cook (2005) argues, conventional ethnography endeavours to speak for participants by describing, while critical ethnography “studies culture in order to change it” (p. 132). This understanding aligns this methodology with the expressed goals of personhood theory and person-centred dementia care, which as Kitwood (1997) contends, strive to disrupt taken-for-granted care practices and calls for a paradigmatic shift in care practice.

In keeping with a person-centred approach, critical ethnography facilitates access to the emic (insider) perspective of study participants and their cultural reality (Foley, 2002). It attempts to bring to light key insights into previously unknown aspects of the culture—in this study, the culture of care within a Canadian long-term residential care (LTRC) facility. Building on Carspecken’s five stage approach to “doing” critical ethnography (Hardcastle et al., 2006) or “performing” critical ethnography (Madison, 2005), Kincheloe and McLaren (2005) contend that critical ethnography has advanced our understanding of culture as a “complex circuit of production” that involves numerous
relational sets of activities, routines, systems of understanding and meaning-making, and conventions of interpretation, relations and conditions that are both internal and external to the social actor (p. 329). Thus, my study is grounded in a critical ethnographic expectation that the researcher enters the world of the “informants” not simply to discover, describe, or explain it, but rather, to participate in the “co-creation” of culture and culture change (Kincheloe & McLaren, 2005, p. 329).

For the purposes of this study, the broader context of “culture of care” is used to describe the social world of the study site where residents, families, direct and managerial care staff members co-exist under a philosophy of care. Critical ethnographers understand culture, in this sense, to be fluid, multilayered, discursively produced, and grounded in material social relations (Kincheloe & McLaren, 2005). Moreover, the critical ethnographer is a “reflexive investigator, who has experienced this unfamiliar cultural space and has dialogued with its practitioners, [and who] can portray this cultural space and its people” (Foley, 2002, p. 473). In the context of LTRC and from within gerontology more specifically, I drew on Kitwood’s (1997) conception of culture as a “settled, patterned way for providing meaning to human existence, and for giving structure to the action within it” (p. 134). Within a dominant culture there are organizations characterized by particular power relationships that produce knowledge, set norms and patterns of (acceptable) behaviour as well as beliefs about truth and what should be within it. This critical lens influenced both data generation and analysis. For example, during the data generation phase of this study, I focused not only on exposing societal disparities that are reproduced in the LTRC culture, but also on ideologies that assisted participants to gain both self-understanding and self-direction.
Guided by critical and feminist theoretical insights and working in the spirit of critical ethnography, I tried to find opportunities to empower participants by drawing on their expertise, or what well-known feminist Donna Haraway (1991) refers to as “situated knowledge,” to find language and knowledge instrumental to the transformation of their work situations and lives in care. Principles of critical and feminist research practice similarly helped me to identify and recognize power relations within the culture of care under investigation and to foreground power relations and the exercise of power within the research process (Ramazanoglu & Holland, 2002).

**Research Process**

In keeping with the critical ethnographic goal of understanding the current conditions and working toward change, multiple ethnographic research methods were used to guide my work. I began by immersing myself in the field, that is, by focusing on the culture of care for an extended period and systematically compiling detailed descriptions over time. The following section describes this process.

**Entering the Field**

Gaining entry or access to the field is a significant challenge to ethnographic research, particularly in the case of critical ethnography. When I proposed this study, I envisioned focusing on one care facility to maximize my ability to achieve a rich, contextualized account of a culture of care. Based on my research focus, I considered only those facilities that were guided by an explicitly person-centred philosophy of care. In my considerations of potential sites, I decided to begin close to home and branch outward. This meant focusing on a facility located in the Lower Mainland of British Columbia. I first approached a facility, which I will refer to hereafter in the interest of
confidentiality using the pseudonym, Cedar Grove, in June 2009. Though I had previously worked for over 15 years in various community and hospital settings in the same regional health authority (predominantly in a therapeutic recreation capacity) and was familiar with the larger context of health care and services for seniors in the region, I had no prior knowledge of this facility. I did not know anyone directly connected with Cedar Grove, nor was I conscious of the facility’s “reputation” in elder care. In addition, I was not known to anyone at the site.

My awareness of Cedar Grove began somewhat coincidentally prior to commencing this study. Because the facility was located close to where I lived, I would occasionally pass by the building and I might casually take note of comings and goings. I recall one sunny day when I chatted with a woman resident who was riding a scooter; she was out in front of the facility with the resident dog, and she spoke to me of her love of the animal and his companionship. This interaction spurred me to do a quick Internet search, which told me that this facility ascribed to a person-centred philosophy. This discovery was exciting; pragmatically, Cedar Grove’s proximity would facilitate easier and more flexible access to the site promoting deeper and varied participant observation of the culture. My decision to approach the organization was then grounded in both theoretical and practical considerations. Cedar Grove fit my research interests because of its person-centred philosophy and because it was in my neighbourhood.

I initially approached the Executive Director (ED) via email. She expressed some interest so I followed up with a lay summary and a description of who I am and the purpose of the study. As per Madison’s (2005) suggestion, I also outlined participants’ roles in the process of inquiry. This document included a list of potential risks and
benefits of participation as well as details related to confidentiality, a possible interview schedule, and a description of the data generation processes (e.g. my use of audio-recording, transcripts, and field notes). From this interaction, the ED agreed to draft a Letter of Support in support of my research ethics application to Behavioural Research Ethics Board (BREB) at the University of British Columbia.

This study received ethical approval January 22, 2010.

**Study Site Description**

Cedar Grove is a not-for-profit residential facility described as a “Campus of Care” that offers a range of housing for elders. The idea of a Campus of Care is unique in LTRC because it offers an array of housing options that range from independent and supportive housing, to complex care, all on the same site or in close proximity. Theoretically, a person could utilize the range of housing offered at Cedar Grove as their situation changes; this creates the prospect for individuals to age in place.

Built in the early 1980’s, the physical design of the facility reflects standards of that period—in other words, its design resembles an acute care hospital. For example, the floor plans on the care floors are “T” shaped, with double-loaded corridors (See Appendix A) and a nursing station, enclosed by a half door, at one end, and two small social spaces, one with a television. There are a total of 44 rooms on each of the four (complex) care floors and 34 rooms on the Special Care Unit (SCU). Although there were minor renovations to the physical design of the facility in recent years, for the most part, the structure and layout of the facility remain a legacy of the period in which it was built. In general, the walls in the common areas and hallways of the facility are painted neutral or pastel colours such as beige, peach and off-white. Evidence of older colour schemes
was also found in some residents’ rooms—hospital blue and greens—but these had been almost entirely phased out. The floors were predominantly white linoleum with black flecks.

All of the rooms are private with a sink and vanity, but some rooms share a toilet and shower. Standard furniture provided by the facility includes; one chair, a nightstand, a single bed, and a three-drawer dresser (See Appendix A). Although space is limited, new residents are encouraged to bring personal belongings and furnishings with them when they move in, and, as a result, the décor in residents’ rooms displayed varying levels of furnishings and personalization. Each complex care floor included a “spa” bathing room that contained a tub and shower, outside this area was another toilet. These bathing rooms were windowless, but efforts have been made to make them a bit less institutional in appearance through artwork. In general, rooms on the complex care floors have residential city views and some residents’ rooms have views of the mountains in the distance.

**Philosophical Orientation at Cedar Grove**

When I began fieldwork, Cedar Grove was in the final months of its affiliate status with the Eden Alternative, a person-centred care model/franchise. This model had been in place for approximately ten years and many members of the leadership team and several direct carers had attended the Eden Alternative (Thomas, 1996) orientation/training sessions required for registered affiliation. I was initially drawn to Cedar Grove because I knew it had this philosophical orientation. For the majority of my fieldwork, however, Cedar Grove had ceased to operate as a registered Eden facility. Despite their official departure though, the organization continued to promote a person-
centred philosophy that challenges the traditional, exclusively medical model of care, and it continued to strive to advance culture change as a means to improving life for the people that lived and worked there. Since its withdrawal, the organization has retained many of the philosophies espoused by Eden; some remnants of language, such as “Elders” and “Neighbourhood,” and some structures, such as “Neighbourhood Meetings” and “Resident Council.”

**Study Sample and Sampling Approach**

This study’s sampling process was designed to obtain rich data on the culture of care. It employed a purposeful sampling strategy (Creswell, 2007), meaning (as suggested above) that I selected the research site (and the potential participants associated with it) because it could purposefully inform the research objectives and questions posed by this study. Within the wider Campus of Care community, my study focused on two floors of the complex care residence: 1) a so-called “usual” or “typical” floor, Juniper Way, and 2) the Special Care Unit (SCU), known as Holly Street. I believed that these two different floors and the care alternatives they represent would allow me to develop an understanding of LTRC from the perspective of residents with different care needs.

1) Residents of Juniper Way lived on a non-secure care floor with elevator access to the main floor for dining, leisure activities, and to go outdoors. The common area on the main floor is furnished with loveseats and upholstered high-back chairs, a grandfather clock, and small, café style tables. Residents could routinely be seen sitting there. A tuck shop was open for several hours three-days per week. Staffed by a volunteer, the shop allowed residents to purchase sweets, personal care items, jewelry, and other small items. A large mantel occupied one wall of this common space and was decorated with
knickknacks and keepsakes. The dining area that adjoined the common lounge area was composed of small square tables that accommodated up to four residents, a large birdcage, and beyond it, there was a small secure patio area with greenery visible to diners. The large kitchen was attached to the dining area where dietary staff members prepared residents’ meals, which were offered with table service.

In addition to the dining room, main lounge, and kitchen, the main floor of the facility also contained administrative offices, a non-denominational chapel, a hair salon, an art room and several bathrooms for residents’ use. Also located on the ground level was the foyer, which was decorated with a few chairs, plants, and a bench that gave the space a welcoming atmosphere. The front desk and Executive Director’s (ED) office were located off the main entrance—the latter of which was visible from the outdoor entranceway. Correspondingly, from the ED office, the outdoor entrance and people’s comings and goings were observable. The main door was secure and required a code to prevent the alarm from sounding.

2) Holly Street, the second site of focus in this study, is a specialized care unit (SCU) for people living with dementia. For the most part, residents of this floor received care, socialized, and participated in leisure programs on the same floor; they infrequently interacted with the main floor physical environment (described above). To make this feasible, there have been structural modifications to Holly Street to add a dining area with a small kitchen and shared social space to the unit. While I was doing fieldwork, this area underwent décor renovations in order to project a more home-like, if sparse, ambience. During this refurnishing, the television was removed from the dining room/common area. Meals for residents of Holly Street were prepared in the main dining area on another floor.
and brought to the SCU on carts. The SCU featured a large garden/terrace that allowed residents’ access to an outdoor area with flowers and plants in raised beds as well as seating areas (See Appendix A). As on Juniper Way, a communal seating area and large-screen television was located in a nook next to the nursing station (See Appendix A). Doors to the stairs on the SCU were locked, and the elevators required a code to operate.

Once the site was selected, and I began initial participant-observation sessions, I proceeded with “within-culture sampling” (Creswell, 2007, p. 129) to generate data through the ethnographic methods of participant-observation (PO) and interviews (described below). I used this sampling strategy to gain insight into the larger cultural group. I used the time of initial engagement in the field to talk with people and make observations of the care culture in order to identify potential participants (cognizant of obtaining diverse perspectives), in light of my research focus (Creswell, 2007; Miles & Huberman, 1994).

In ethnographic research, this process is often referred to in terms of the identification of “key informants” (Maxwell, 2005), for example, care staff who are well-informed and accessible and who might provide feedback that would allow me to critically examine my own and other lines of thinking about the culture. Keeping in mind the problematic nature of relying on “key” informants and the power relations implicit in ethnographic practice, it was crucial for me to respect the importance of developing a set of trusting relationships with knowledgeable members of the culture under investigation (Foley & Valenzuela, 2005). Inclusion criteria for interviews and PO then, required involving staff, residents and family members from each of the two units of the care facility as well as administrative staff who oversaw the entire facility. Individuals were
excluded from participation for the following reasons: 1) their inability to consent and/or assent (in situations where a substitute decision-maker was unavailable to provide consent; and, 2) limited ability to communicate in English.

In total, I conducted approximately 300 hours of PO and 23 individual in-depth interviews with people whose daily lives are connected to the culture under study.

There were four groups of participants:

1) Administration: This leadership team is composed of an Executive Director and eight directors from the following service areas: residents, food/nutrition, leisure, and volunteers, as well as professional practice, information systems, and building maintenance. All but one of the leadership team is a woman and all are trained professionals and English-speaking of European ethnicity. The age range was mid-thirties to mid-sixties. Interviews with these individuals generally took place in the director’s office, and of the four categories of interviews undertaken, these were logistically the easiest to arrange and conduct.

2) Staff: This category is comprised primarily of Resident Care Aides (RCAs) because they provide the majority of the direct care work at Cedar Grove. They implement residents’ care plans, under the supervision of the RN or LPN. A large part of their role includes assisting residents with personal care (such as, bathing, dressing), but they also play a crucial role in observing and reporting residents’ behavioural or medical changes. Also included in this participant category were nursing staff, Registered Nurses and Licensed Practical Nurses and leisure staff because of the primary role these members of the team perform in care planning and front-line care. These three groups have been
combined under the “Staff” category to assist with the goal of anonymity, but at points in the writing of this ethnography, I have had to differentiate their roles. Unlike RNs and LPNs, the licensing and training of RCAs is less stringent.  

The direct care population at Cedar Grove was an ethno-culturally diverse group composed predominantly, but not exclusively, of women of colour. At the time of data generation, the average length of employment of direct carers at Cedar Grove was 10 years. Many of these staff are employed on a part-time basis and their hours are shared for facility-wide coverage. The exception here is on the SCU where one leisure staff works 6 hours per day, Monday to Friday. Interview locations for these participants varied, from lounges in the facility, to cafes and restaurants in the adjoining neighbourhood.

3) Residents: The study site’s resident population reflects LTRC trends generally. That is, it includes increasingly older people, the majority of whom are women, and who possess complex care needs (McGregor et al., 2010). During fieldwork, approximately 75% of the residents at Cedar Grove were woman with an average age of 81 years. Also characteristic of current LTRC, approximately 80% of Cedar Grove residents lived with challenges associated with dementia.

4) Family Members: This portion of the care culture proved the most difficult of the four groups to meet at Cedar Grove, let alone to invite to participate in an interview. This methodological challenge reflects the demographic realities associated with residents’

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2 Some of the RCAs on staff completed a recognized RCA program. Although there is provincial variation in education and training for RCAs, in BC, a typical certificate program involves an approximately 4-6 month course that includes classroom, home study and practicum experience. Also specific to BC is the presence of a registry that seeks to improve standards of care in the RCA community (http://www.cachwr.bc.ca). In 2010, British Columbia established the British Columbia Care Aide and Community Health Worker Registry that requires RCAs and community health workers in BC who have graduated from a training program to register. At Cedar Grove, RCAs are registered on this list.
social situations: only 33% of the resident population had a family member actively involved in their care during the period of my fieldwork. Reasons for this varied, but one might say that this situation reflects broader socio-political trends whereby current economic pressures contributes to the geographical dispersion of nuclear families, people living longer, and generally less connected/supportive social networks (Gilbert, 2006; Sibley, 2006)\(^3\).

**Recruitment and Consent**

To achieve multiple points of view on the research questions, from a range of perspectives or “subject positions” (Agger, 1991), I sought to cultivate relationships in the field with representatives from the above four groups. Recruitment and involvement of participants reflected feminist, critical approaches that are clearly linked in their conceptual focus and ideological commitment to addressing and rectifying disparities of social power and position. To this end, I worked toward making participants feel comfortable by drawing on my skills as a researcher and my experiences working with people with dementia and other care staff in facilities across a variety of community and hospital settings. This expertise helped me to gain and maintain participants’ trust.

While this study generated data from a variety of sources and methods, I began with a prolonged period of engagement, during which I worked predominantly as an observer or a participant-observer in the field. To ensure that all parties were clear about the function and expectations of this fieldwork, I consulted with the leadership team to strategize how best to make my presence and purpose known to the community. It was

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\(^3\) The lack of familial support or connection among the resident population has important ramifications for understanding person-centred approaches to care that tend to prioritize and assume greater levels of family involvement than those observed at Cedar Grove, which research points to as representative of current trends in LTRC.
decided, in the interests of efficiency and scope, that during my initial time at Cedar Grove, I should attend various staff meetings to present my study to all levels of the care team. These group presentations were supplemented by my attendance at brief daily staff meetings and one-to-one conversations with staff, residents and others regarding the study. Research posters containing my photograph were also placed in prominent locations throughout the facility (See Appendix B). During fieldwork, I always wore a nametag, identifying me by name and position (student researcher).

My comfort working with older adults, and persons with dementia specifically helped me to engage resident participants without coercion. This was critical to developing an ethical approach to this qualitative study. The idea of gaining “informed consent” in ethnographic research, particularly in health care settings, is fraught—not only because of the power relationships between researcher and participant, but also because of the complexities and practicalities of observation in public settings (Murphy & Dingwall, 2007). As Kitwood (1998) tells us, “a person who has dementia is, ipso facto, relatively powerless” (p. 155). Tinney’s (2008) research on negotiating boundaries and roles in nursing home ethnographic research cautions researchers when determining the extent to which consent is given voluntarily, to be alert for participation that may stem from loneliness or a desire to please. To address this possibility, at least in part, recruitment was guided by the participatory research model set out by Dewing (2007). Built on feminist ethics of care, this method stresses the importance of relationship in the research process and of employing an “inclusionary approach to consent” (p. 13). Guided by this “process consent method” (Dewing, 2007), the initial stages of recruitment of resident participants might be better understood as “permission for access” (p. 15), as
opposed to proxy consent: I spent time with the residents to ascertain his or her interest and ability to participate. Once interest was established, consent was revisited and re-established at each meeting with the participants, ascertaining that the person was comfortable with participation.

In order to achieve subjective insights into a variety of residents’ experiences, I spent time with residents of different degrees of cognitive ability: those not diagnosed with a dementia, as well as those diagnosed with mild-moderate to severe dementia. Depending on the presence/degree of impairment, I engaged in PO sessions, informal conversations, formal interviews, or Dementia Care Mapping (DCM – described below). Finally, because care can be understood to occur within the context of a triad composed of the person with dementia, the family member (s) and the staff carer (Adams & Gardiner, 2005), the involvement of residents’ family members was also sought (See Appendix E). The residents who participated in the individual interviews were all able to provide consent at the time of participation. This was demonstrated through their ability to relay an understanding of the reason for my presence at Cedar Grove, purpose of my study, and their involvement in it. Each of the resident participants was female, reflecting the gender composition of Cedar Grove and LTRC in general.

**Data Generation**

Fieldwork took place over a 12-month period, with intermittent contact over subsequent months (February, 2010 – April, 2012). As an inductive, qualitative investigation, the research design had a relatively high level of flexibility built in, which allowed me to respond and adapt to situations in the field regarding the use and appropriateness of the various methods. During this time, I endeavoured to blur some of
the lines between the researcher and the “researched” described by Madison (2005), in part, by developing rapport, a feeling of trust and comfort, with participants. This study was conducted with the postmodern understanding that all knowledge is “partial, in the sense of ‘not-total’ and ‘not-impartial’” (Ramazanoglu & Holland, 2006, p. 66). As Ray (1996) asserts, a postmodern orientation cautions, “every theory provides both a way of seeing and a way of not seeing” (p. 674). Establishing and maintaining a “position of passivity” was not the goal of this study. Not only did I seek to involve myself in everyday life of Cedar Grove, when and wherever appropriate, but individuals from the care community were encouraged to actively participate in numerous aspects of the research project.

To respond to the research questions posed in this study and to build interpretation that is rooted in a critical epistemology, this study relied on a multifaceted process of data generation, guided by the directive to “make the work visible in a different way” (Denzin & Lincoln, 2005, p. 4). The ethnographic methods I used to generate data include: participant observation (PO), in-depth individual (conversational) interviews, group meetings, Dementia Care Mapping (DCM), and archival review of organizational documents, policies, staff communications, and health authority documents. Verbatim transcripts were made of all interview sessions and field notes were recorded for all observation sessions, including factual information and reflexive memoing to build in critical reflexivity. Observational data sources also included researcher-produced photographs. When possible, I engaged in member checking by making transcripts available to participants in order for them to see how their views are
represented and, in keeping with an iterative approach, to permit clarification and editing (Foley & Valenzuela, 2005; Hardcastle et al., 2006).

These multiple methods allowed for the triangulation of findings, that is, for the same phenomenon to be understood from various angles (Morse & Field, 1995). This adds to the credibility of the findings, and ultimately, contributes to my goal of “constructing a multilayered” (Atkinson & Delamont, 2005, p. 828) contextualized account of the social world of a person-centred LTRC facility. Each of these methods will be discussed below.

**Participant Observation**

The primary method of data generation in this study was participant observation, with fluctuating levels of participation depending on the stage of the research and what was going on in the research site. Following Creswell (2007), observing in this study involved a series of steps that allowed me to transition over time from observation conducted by an etic or “outsider” to more of a participant-observer or an emic perspective of an “insider.” In critical ethnography, the participant-observation designation indicates that researchers are not neutral, passive observers, but rather, active participants in various degrees in the research site. Nursing home ethnographers have taken up participant observation (PO) in a variety of ways—from training and working as a nurses’ or care aide (Diamond, 1992; Henderson, 1995; Kessler, 2007; Lopez, 2006a, 2006b), to volunteering (Tinney, 2008), to a more traditional (“hands off”) observer position in the field (McLean, 2007b). My role was more consistent with the ethnographic approach taken by McLean (2007b).
In total, I conducted approximately 300 hours of participant observation: these sessions took place at different times of the day, on various shifts, day and evening, and on both weekdays and weekends (when staff coverage varied and fewer care staff in general was present). My experience during these earlier PO sessions revealed that residents retired to their rooms early, generally by 7:00 pm; so in the interest of observing “activity,” I tended to restrict my sessions to the daytime. I did conduct some early morning PO sessions however, having learned from staff that there were several early risers (5 am or 6 am) on the SCU. In general, my initial PO sessions lasted for periods of three to seven hours, and then tapered overtime to one to three hours per floor.

The core activity of PO involves not only immersion in the field, but also the production of written accounts of the social world under investigation. Field notes taken at this time were both descriptive and reflective (documenting my impressions and hunches), and they might be seen as a representation of the day-to-day events at Cedar Grove—that is, these notes helped produce a written account, a “construction” of the field based on a selection of events. As Emerson and colleagues (2007) suggest, my field notes “inevitably present or frame the events and objects written about in particular ways” (p. 353) and were crucial in my understanding of key findings discussed later in this study. Field notes were transferred to an Atlas.ti database for coding and analyses, a practice that will be expanded on later in this chapter.

During PO sessions, I jotted down notes and verbatim snippets of conversation, which I would later develop into a narrative of the PO session. I used these sessions to reflect on my position in the field. These reflective notes capture aspects of daily life and practice as they relate to power not only in the culture of care, but they also shed light on
my methodological approach including both research process itself and my subjective place in it.

Because of the noted uniqueness of the two floors in relation to physical layout and the day-to-day activities that occurred in these spaces, PO sessions were conducted in distinctive ways. For example, on Juniper Way, the sitting room was a place where many of the residents who were immobile and/or more cognitively impaired than other residents were located. Because of this, my PO sessions conducted in this social space contributed to my connection with these residents. Being in the sitting room also meant that in the absence of care staff, I was also called upon to help with the TV remote, changing channels on the large television as instructed by the group. These PO sessions were dominated by interactions with its female residents, with largely cursory contact with the few men who although they lived on the floor, generally did not congregate in the TV area. Residents who were independently mobile did pass by and would often chat on their way to the elevator en route to the main floor where meals were served and scheduled leisure activities took place (See Appendix A).

During this early period, several residents invited me on a tour of their rooms. In this way, I was able to gain vital insights into these individuals’ private living conditions. These tours allowed me a window into aspects of residents’ life histories that otherwise would have remained out of view. That is, these visits revealed vital aspects of residents’ familial and social networks, usually through a discussion of their personal photographs and meaningful objects.

The PO sessions on Holly Street were markedly different. As a secure unit, the social space of the SCU also functioned as the dining area. As a result, I was able to
transition more easily while there from a more traditional “hands off” (McLean, 2007b) observer to a more active participant-observer, involved in assisting some residents with their meal (under the direction of nursing staff). It also meant that I sought staff assistance for residents as required. Unlike on Juniper Way, many of the Holly Street residents, also predominantly women, were more likely to be mobile.

In an effort to access these culture members’ experiences, challenged by the presence of dementia, I employed the simple technique known as “walking with participants” (Carpiano, 2009; Pink, 2007). Pink (2007) highlights how social anthropologists have long sought to understand culture members’ by joining with them in variety of activities and that more recently walking has gained attention in the field as a vital way to access and share in informants’ “corporeal experiences” (p. 244). She refers to walking as an “(almost) universal activity” (Pink, 2007, p. 244) and indeed many of the residents of the SCU spent a lot of time walking. This way of being with the residents helped me reflect on and appreciate individuals’ bodily engagement with the world (Kontos, 2005; Kontos & Naglie, 2007; Phinney & Chesla, 2003). During Holly Street PO sessions, I spent a lot of time walking arm-in arm with one or often more of the residents in order to get to know them through this embodied research experience. If the weather was nice and the doors onto the terrace were open, these walks took us outside, where we could talk about, pick, and smell the various flowers, plants, and the vegetables contained in the pots and raised beds.

Spending time walking—and sometimes dancing—with residents allowed me access to residents’ bodily engagement with the world. These “bodily encounters and interactions” (Dyck, Kontos, Angus, McKeever, 2005, p. 176) with individuals who lived
in the SCU helped me to consider the day-to-day life of persons with (moderate-severe) dementia in several ways. They gave me insight into how they interacted with the physical space of the SCU. I experienced with them how they moved through it and gained insight into how they were constrained by the physical space of the SCU. For example, I was made aware of the doors that blocked their paths or attempts to use the elevator to leave the floor. On many occasions people would ask me where the bus was or how they might get “downtown.” These encounters were emotionally difficult for me to deal with—I found the feelings they generated difficult to shake. Being part of residents’ distress, bodily and psychically, was an emotionally challenging part of fieldwork, because I often felt helpless and ill equipped to make them feel better in the moment.

In addition to these more independently mobile residents, the SCU was also home to many other (mostly) women who were further along in their disease, immobile and restricted to a medical recliner when not in their rooms. Often, these residents were seated together for meal and social times, at tables located near large glass doors that open onto the terrace. Without mediation, interactions with these individuals were difficult to manage, so I sought out and was informally guided by care staff regarding these residents’ personalities, social histories, their likes and dislikes, and so on. As a researcher, my access to these culture members made it hard to develop meaningful connections with them, which meant therefore that they were easier to neglect during fieldwork. This realization came to the fore during DCM sessions and will be discussed later.
Another unique characteristic of the SCU was that leisure activities (such as, music and horticultural therapy) and various celebrations (birthdays and seasonal events) took place in the communal dining/social space. Celebrations in the SCU attracted people from other parts of the Campus of Care, and they permitted me access to interactions of Holly Street residents with the wider community. Participating (while observing) in these parties also allowed me to get to know residents in a socially relaxed setting, by engaging people in dancing and singing and helping out with drinks and snacks. Like walking with residents, this interface also proved to be an invaluable resource for observing and interpreting residents’ physical interactions with their social world in a way that did not privilege verbal communication, as many qualitative methods do.

**Shadowing**

Following Reed-Danahay (2001), my participant observation research included seven “shadowing” sessions with direct care staff. For each of these sessions, I took detailed notes that helped me to understand the direct care staff role and gain insight into the interactions between staff and residents. Consent for shadowing sessions as well as for access to residents’ private spaces was negotiated with staff and residents prior to commencement. Given that many care interactions took place in residents’ rooms, I considered this access an important part of my investigation.

**Summary of PO at Cedar Grove**

The PO sessions on both floors allowed me to interact with care staff members, observing their interactions with one another and residents, and with maintenance staff, the occasional family member and volunteers. In this way, I came to appreciate the
rhythms of the day at Cedar Grove. On both floors, the social spaces were also locations for care interactions, where nursing staff provided occasional care (e.g., medication distribution, personal grooming, and attending to a variety of personal needs).

As vital elements of my inductive study, PO and shadowing sessions facilitated insights not only to the research focus of this study as originally proposed, but also to aspects of the care culture that I had not considered prior to engagement in the field. Moreover, they helped me to determine who best to interview (key informants). At the same time, they assisted in improving the quality of the individual interviews by facilitating my understanding of the cultural relevance of different behaviours, language and experiences I witnessed.

**Visual Data: Researcher-Produced Photographs**

During fieldwork, I took over 300 digital photographs on both Holly Street and Juniper Way. Photographs were used as both a “medium of inquiry” and a “mechanism for reporting research findings” (Shenk & Schmid, 2002, p. 242). As a medium of inquiry, I took photographs of aspects of the culture related to the built environment, which were then explored in relation to this study’s conceptual framework. As Atkinson and Delacourt (2005) note, “most ethnographic reportage seems oddly lacking in physical location” (p. 827). To supplement the “sketchy” descriptions that I had written in my field notes, I decided to create a visual record of the places and spaces that “social events and encounters take place” (Atkinson and Delacourt, 2005, p. 827). These photographs (a selection of which are included in the Appendices) then were a resource that added a visual dimension to this study (Harrison, 2002), helping to inform my analysis of field notes and bolstering the mental or head notes that field notes tend to evoke. This visual
record became part of my “ever evolving memories of the field” (Coffey, 1999, p. 127).
As a medium of inquiry, visual data document and explore aspects of the facility’s physical design vis-à-vis tenets of person-centredness and considerations of the influence of the physical environment on the social world(s) of Holly Street and Juniper Way. With this in mind, I photographed residents, and residents and staff, at various social gatherings. Photographs of residents engaged in a variety of activities also helped to add detail and depth to field notes and analyses.

Another purpose of producing photographs was to obtain a visual record of the study site to document aspects of the physical design to facilitate analysis of the environment. These images highlight spatial components of care and the influence of the physical environment of the daily life of residents. These photographs permitted another perspective on how the physical environment influences social connectedness at Cedar Grove. They are a visual record of the physical environment that facilitated analyses of data of the facility in relation to understandings of space, the institution, and Othering. In particular, the visual data helped make sense of considerations of space with power (Augé, 1995; Foucault, 1963/2003, 1967/1984, 1977/1995; Goffman, 1961/1991; Soja, 1996) in the LTRC, as well as person-centred theory in practice. Both scholars consider the spatiality of human life, with space being a fundamental consideration in the exercise of power. A selection of these photographs is found in the appendices.

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4 Although these photographs were for my analysis only, I did distribute them within the facility to the people involved. If I were to use these photos in future, according to my ethics application, subjects would need to sign a release form.
**Dementia Care Mapping**

In addition to the less structured PO observation, Dementia Care Mapping (DCM) provided a more structured approach for observing. It was selected because of its strength as a clinical evaluation tool to measure quality of care in formal settings. DCM was designed to appraise “good quality person-centred care” (Brooker & Surr, 2005, p. 18) and was used to supplement PO sessions. After several sessions, I noticed the absence of residents with more advanced dementia reflected in the data set. To address this, I made a conscious, methodological decision to concentrate on several residents with more advanced dementia and to try and map their experiences of care. Their perspectives, while difficult to access and easy to overlook, proved crucial to my larger study and the findings generated. Importantly, DCM supports insights into non-verbal expressions of personhood and bodily communications between residents and their social environment, as well as non-verbal communications during care interactions, so it is particularly effective when observing people with advanced dementia and limited verbal acuity.

DCM was initially developed by Kitwood and Bredin (1992) and was designed to measure the degree to which person-centred principles are evident in a care environment (Innes, 2009). It is based on the philosophical proposition that, “If personhood is maintained, then the participant will be observed to be in a relative state of well-being” (Brooker & Surr, 2005, p. 21). As an observational tool, DCM has the recognized ability to assess care and inform care practice; it is valued as an important way to access and foreground the perspective of persons with dementia, perspectives that are historically excluded from research (Cotrell & Schultz; 1993; Dewing, 2007; Innes, 2002a; Moore & Hollett, 2003, O’Connor et al., 2007). DCM also points out the ways in which carers and
the overall social environment support personhood and contribute to well-being. States of well-being can be identified when a person with dementia displays behaviours, such as eye contact, affection, or initiating contact with others (Capstick, 2003).

Dementia Care Mapping in its standard form involves “mappers” observing and making qualitative notes regarding residents’ experiences and activities over a representative time period (Brooker and Surr, 2005). According to DCM guidelines, after each five-minute interval, individuals are assigned one of two types of codes: a Behavior Category Code (BCC) and a Mood-Engagement Value (ME). These are supplemented by notations on personal enhancers or detractors.

**Behavior Category Code (BCC):** There are 23 BCC to select from and individuals are assigned one based on behaviour that occurred during that time frame such as "Expressive," “Articulation” or “Physical” (Brooker & Surr, 2005).

Within the BCC, the behaviour of the person being observed is divided into those of high, moderate, or low potential for well-being (Brooker & Surr, 2005). An example of a high-potential BCC is “E” for Expressive, assigned when a person is taking part in a sing-along. “B” connotes borderline behaviour, a moderate potential code, where the person with dementia is observed as passively engaged in their social environment, such as when watching a musical performance. A low-potential category is coded “C” for Cool, assigned when a person being mapped appears to be totally uninvolved and withdrawn from their environment.

According to DCM operational rules, BCCs of the highest potential take precedence over those of moderate or low potential. As Capstick (2003) points out, this aspect of DCM has been critiqued for its emphasis on so-called Western values of
achievement through activity. In other words, DCM evaluations of residents’ engagement may present a more positive picture of the care environment than actually exists and moreover, assessments of behaviour and mood may fail to consider non-Western indicators of well or ill-being. The corollary of the valuing of activity has also been identified in the literature as DCM’s inability to assess, for example, when a person is engaged in passive reflection (such as when meditating or praying) as opposed to the negative behaviour of being withdrawn.

**Mood-Engagement Value (ME):** These are the second code assigned by the mapper and this code is based on the affect and level of social engagement observed in the person with dementia. The ME value ranges from +5 to -5 and covers the spectrum of mood and engagement from cheerful and happy, when someone is deeply absorbed in an activity, to distressed and withdrawn, when someone appears to the mapper to be disengaged from the activity.

**Personal Enhancers (PE) and Personal Detractors (PD):** In addition to BCC and ME scores, the DCM tool also includes interpretation of care practice in terms of what Kitwood (1997) referred to as “Personal Enhancers” (PE) and “Personal Detractors” (PD). Kitwood described episodes of Positive Person Work in practice whereby care interactions serve to meet the psychological needs of persons with dementia, or contrastingly, to undermine them. Psychological needs include the following: comfort, identity, attachment, occupation, and inclusion (Kitwood, 1997). In practice, this means that when I observed an interaction between staff and a resident in which the resident was made to feel safe, valued, or provided with sense of belonging, this interaction was understood to uphold their personhood. In this situation, I would make note of this
positive interaction and assign the appropriate PE, such as warmth and inclusion. Conversely, if I observed a care interaction in which the resident was ignored or infantilized, then I assigned the appropriate PD, for example, ignoring and mockery. As per the DCM 8 User’s Manual, the 17 PEs and 17 PDs can be further subdivided into enhancing or highly enhancing episodes, or contrastingly, detracting and highly detracting episodes of care.

Typically, at the end of a period of observation, results are analyzed and fed back to the care team with the intent of affirming good care practice and when indicated, highlighting areas that require more work toward more person-centred practice. For this study, DCM was used in a research capacity as an observational measure of the resident participants’ relative well-being during the course of daily life.

I received basic training and certification in DCM in 2006 through an intensive three-day course offered through the University of Bradford and the first mapping session I conducted at Cedar Grove took place following over 100 hours of PO. During this time, I became increasingly interested in unstructured activity and how a resident’s day unfolded between meals, care and opportunities for leisure programs. In mapping sessions, I targeted weekends and evenings to access times when there tended to be less structured activity. This helped me to understand the experiences of residents between programmed activities, and to gain a thicker description of their everyday life. In total, I conducted 24 hours (8 sessions of 3 hours each) of DCM in the social/dining area of Holly Street (the SCU), and 6 hours (2 sessions of 3 hours each) in the sitting room of the “usual” floor, Juniper Way. The differences in time devoted to DCM for both these sites related to the unique characteristics of the two floors. On the SCU, residents and staff
used the social area constantly, for a variety of activities—eating, social events, and for unstructured activity. In contrast, residents used Juniper Way’s social area, almost exclusively to watch the television, hence there was little else for me to observe.

To prepare for the mapping sessions, staff was briefed on the intent and process of DCM during leadership meetings and daily meetings with direct carers on the care floors, permitting me the opportunity to respond in person to questions and concerns voiced by staff. In addition, family members were notified by administrators in a newsletter a month in advance of the research generally, and of my intent to use DCM on the care floors’ social areas. As well, I was in contact with the Executive Director to assess if any questions/concerns came forward that I was unaware of—there were none. Following DCM guidelines, on mapping days, carers and residents and/or family were again notified by posters of my purpose in the space. Finally, while mapping, I responded to individuals who were curious about what I was doing and why.

Conducting DCM sessions in the social spaces of Holly Street and Juniper Way (a principle of DCM is that mapping be confined to communal areas), not only drew on my empathy and observational skills, but it also allowed me to obtain systematic insights into care practice from the perspective of the resident with dementia (Kitwood, 1997). Data generated through DCM helped support insights into how personhood is maintained and/or undermined in the care environment and offered important insights into personhood and resident well-being—fundamental concerns to this investigation.

**Group Meetings**

As part of my fieldwork and research process, I participated in four, daylong group meetings with staff (February, 2010 – November, 2011). My contribution to these
meetings involved a presentation of emerging findings that focused on practice and the social aspects of care. The content of this presentation was largely based on DCM analyses, supplemented by PO and interview observations. During these events, staff from all sectors of the care team exchanged opinions and experiences related to care practice and culture change. These meetings allowed me to present and receive feedback on emerging findings, thus functioning as an organic mode of data generation and member checking in a group context. This feedback was captured through: 1) field notes documenting verbal comments/questions posed during the presentation of the data; and 2) evaluation forms completed by participants following each meeting (See Appendix C).

This feedback provided an important means of checking biases or assumptions that may have negatively influenced my interpretations and analyses, which in turn contributed to my goal of co-produced findings. These meetings enabled me to obtain insights into group dynamics and cultural beliefs in a naturalistic setting, which was very different from a focus group setting, for example. Following the meeting, I distributed evaluation forms to staff, asking for input on what individuals had seen in my presentation, querying what made sense to them, and asking them to elaborate on what I seemed to neglect in relation to their practice at Cedar Grove. Of the 84 forms distributed, 59 were returned to me, for a response rate of 70%.

Importantly, these meetings enabled me to tap into key aspects of care practice and organizational policies as they relate to the caring that hinder or facilitate culture change. They helped me discover from carers as a group what mattered to them, how they made sense of their world, what aspects of culture change goals/messages resonated with them, as well as what did not. Moreover, these meetings provided invaluable access
to verbal and non-verbal forms of communication, group interactions, and understandings of the discourses in use and the movement/use of power in the culture of care.

These meetings were different from the majority I attended during my fieldwork, and it is important to note that during the meetings, I was a presenter and I became more closely aligned with administrators, particularly in the eyes of care staff. This in turn impacted the kinds of data generated. These events were attended by a cross-section of staff: they ranged from 20-30 carers, of which the majority worked as RCAs, 2-3 were LPNs or RNs, 2 family members, and the remaining participants were members of the leadership team.

Other group meetings that I attended, made field notes on, and that ultimately shaped interpretation included: care conferences Annual General Meetings, council meetings for family and residents, a picnic outing for residents and families, and many other staff meetings, both formal and informal. Overall, these events were vital to descriptions and interpretations, or as described by Holstein & Gubrium (2008), the “what and how” questions of this ethnography.

**Individual Interviews**

Individual interviews with various levels of care staff, members of the leadership team, residents, and family members helped move interpretation in this study beyond description to deep, emic, understandings of the culture of care. Individual interviews were designed to gain insights into care staff members’ perspectives on their work environment; thus, these interviews began with questions that accessed broad understandings of care staff’s role within the care team and opinions on person-centred approaches to dementia care. Probes were used to develop interpretations. These
interviews were open-ended and conversational in style, an approach that is important to qualitative inquiry because it increases the likelihood of generating unanticipated responses and insights from participants (Hammersley & Atkinson, 1995; Rubin & Rubin, 1995). Interviews were held wherever the participant felt comfortable. Generally, for members of the leadership team they were conducted in their office, while direct carers and family member interviews were conducted off-site. All resident interviews took place in their private rooms.

Individual interviews lasted from approximately 30 minutes to two hours. Four direct care staff were interviewed once respectively, while one other carer was interviewed on two occasions (for a total of five interviews). All personal interviews were audio-recorded. These interviews were supplemented with ad hoc contacts (for example, in hallways) that were generally not audio-recorded but were useful for clarification and elaboration of points raised during the initial interview. These interviews took place later on in the fieldwork period when it was hoped that there was some trust built in the relationship between researcher and participant, as well as to permit a more nuanced interpretation of participants’ stories, views and opinions. Individual interviews also took place with five members of the leadership team. Three were interviewed once, one person was interviewed twice, and one person was interviewed three times (for a total of eight interviews). A total of four interviews were conducted with family members. Finally, I engaged three residents in two conversational interviews each (for a total of six interviews) in order to obtain their vital perspectives. Interviews with residents were arranged when I deemed that these individuals had sufficient cognitive and communicative ability to provide informed consent.
**Review of Relevant Documents**

This study also included a review of the organizational documents and relevant policy documents related to LTRC. “Documentary analysis is significant insofar as a given social setting is self-documenting and important social actions are performed in that setting” (Atkinson & Delamont, 2005, p. 823). To this end, I reviewed internal organizational policies and procedures documents from the facility. Examples of documents in the organizations’ “historical archive” included staff communications, organizational strategic plans, Annual General Meeting reports, accreditation reports, job descriptions and minutes from various council and staff meetings. Also, as this study’s critical approach locates the culture of care within the broader socio-political environment in which it is embedded, I also reviewed relevant policy documents/governmental reports related to long-term residential care in the province and nationally. Together, this record allowed me to explore what “uses” (Atkinson & Delamont, 2005, p. 823) these documents served in the culture as they materialized, or not, during PO, individual interviews, group meetings and DCM.

**Data Analysis and Interpretation**

**Introduction**

In this section, I describe the strategies I used to transform data into study findings (Patton, 2002) and the various issues that emerged during this process of ethnographic analysis. In the qualitative research literature, the purpose of analysis is often to reveal patterns or themes in the data, which then lead the researcher to the interpretation of the identified themes. These themes are considered as “evidence” in
relation to the questions posed by the research. Critical research problematizes the apparent straightforward nature of the above description. Coffey (1999), for example, states that in fact analysis, the act of “doing analysis,” is a highly personal endeavour. Denzin and Lincoln (2005) contend, “Qualitative research is a situated activity that locates the observer in the world” and its practices “turn the world into a series of representations, including field notes, interviews, conversations, recordings and memos to the self (p. 3). Understanding the qualitative researcher as an “instrument” of research (Finlay, 2002), it follows that the decisions I made around analysis, what I considered to be important in the data, and ultimately what counted as “evidence,” were a function of a combination of theoretical and epistemological orientation, the purpose of the study, and reflective of my “ethnographic self” (Coffey, 1999). Leibing and McLean (2007) refer to this mix of personal and formal processes that occur during fieldwork as “the shadow side of fieldwork” (p. 2). These researchers use “the shadow” not only as a metaphor for what is exposed in research and what remains hidden, but also as a way of exploring and representing one’s experiences in the field, of what is seen and unseen, while engaging in a reflexive account of how a researcher’s own shadows impact what they study.

This critical ethnography draws on the epistemological influences of postmodernism. More explicitly, it aims to challenge the status quo or disrupt “taken-for-granted assumptions by bringing to light underlying operations of power and control” (Madison, 2005, p. 5). The expectation is that through the process of critique social conditions might be improved. To this end, data analysis and interpretation were a part of every aspect of my research and fieldwork, which is consistent with this orientation (Ramazanoglu & Holland, 2002). This study was iterative, involving the repetition of
steps involved in data generation, management and analysis as needed to refine interpretation, fill in gaps, and extend interpretation of the culture of care. That is, data was revisited many times in order to facilitate the further development of meaning and to spark new insights that could then be checked out in the field (Srivastava & Hopwood, 2009).

Consistent with ethnography, interviews were conversational in style (Foley & Valenzuela, 2005; Hammersley & Atkinson, 1995; Rubin & Rubin, 1995) and audio-recorded and transcribed verbatim. These interviews took place in each of the residents’ private rooms at a time that was convenient to them. Unlike my practice with other participants I interviewed, I did not return the transcripts to resident participants. The reason for this was the vulnerable position they are in with respect to privacy: I could not ensure that staff could not view the document, thus breaching confidentiality and potentially jeopardizing the resident’s safety. To offset this, in part, I requested more frequent clarification of the meaning/intent of their comments—a form of member-checking—during the interview and re-visited the topic in the second interview or discussion.

As is common in qualitative inquiry, data management was a significant challenge in this study because of the large quantities of data it generated. To assist with textual data, I used computer assisted data analysis software, ATLAS.ti, to systematically analyze field notes, transcripts and other textual data. This software also helped with the coding and annotating of the data, as well as with weighing and evaluating of their significance. DCM data analysis followed operational rules as described in DCM 8
(University of Bradford, 2005) that produced individual and group well-being and ill-being scores and the development of individual and group profiles.

Overtime, the data analysis process allowed me to produce common codes and then to develop groups or categories of codes into themes. Emergent themes not only reflected the research focus, as outlined by the conceptual framework, but also themes that were unforeseen from the outset, those of significance in the culture.

I will now outline the process of data analysis and interpretation used in this study.

**Data Analysis**

Data analysis was guided by the theoretical approach of critical ethnography, beginning in a preliminary way through field note-taking and continuing throughout the study. In total, I completed field notes for 86 participant-observation sessions. Initially, field notes recorded descriptive, factual points observed at the site. For example, I kept notes on noise levels, lighting, smells, who was there, what they were doing, and so on. Eventually, field notes became more analytic, developing the meaning of my observations and the questions raised during PO while making tentative interpretations. In these notes, I would record the timing of the observations and the behaviours of participants as they went about their day. Temporality became an increasingly important aspect of analysis, as I came to recognize the significance of time in the LTRC context. For example, I would record the length of time a resident was engaged (or not) in an activity, or how long a care interaction lasted (this aspect of life in care was influenced by DCM practice in which participants’ behaviours are recorded at 5-minute intervals, over a period of several hours). I was also interested in the spatial organization of LTRC as a
key part of this inquiry, and therefore details on the physical environment were photographed, recorded and analyzed in relation to participants’ behaviours within a given space. Given that communication is in part a bodily act (Kincheloe & McLaren, 2005) and that some forms of caring behaviours are non-verbal, and because key aspects of the self are expressed physically, notes on body language and interactions were also documented.

**Coding and Thematic Analysis**

During my active involvement in the field, the practice of producing, reading and re-reading field notes, in an attempt to continuously engage with and reflect on the data, was instrumental in the process of initial and subsequent coding. From my research questions, I developed a codebook for the textual data, an evolving document that influenced concurrent PO sessions and interviews. Examples of early codes that were more concrete and might be described as “low-level coding” (Carspecken, 1996) were, “Biomedical View,” “Life History,” “Mealtime/Food,” and “Job Satisfaction,” and “Meaningful Activity.” From the outset, I was interested in methodological issues related to fieldwork, and so early on, I began coding PO and interview data that addressed issues of ethics in research and the challenges of recruitment under the code “Methodology.”

Categories that tapped into person-centred practice, such as facilitators, obstacles, and evidence of the organization’s care philosophy and personhood support were also identified from the outset. Over time, as my familiarity with the nuances and subtleties of the care culture increased, and through consultation with participants and my constant re-reading of the transcripts, my coding became more refined, and I was able to adopt a more critical lens. Examples of later more “high-level” coding (Carspecken, 1996)
included; “Social Location,” “Alterity,” “Agency and Resistance,” “Citizenship,” and “Surveillance.” As I came to better understand the social patterns of the group and what was significant to the people who lived and worked at Cedar Grove, I added codes that reflected issues that emerged from the care culture, such as, “Mobility,” “Waiting,” and “Television Viewing.” This systematic process of coding of field notes was supplemented by concurrent reviews of the other data sources as well as on-going conversations—formal and informal—that helped identify issues of most importance to members of the culture. The development of coding and the questions that surfaced through this process and the creation of what Madison (2005) describes as the creation of “code clumps” (p. 36), facilitated the identification of categories and then themes, thus ensuring that the analysis was data-driven (Sandelowski, 1993). Examples of emergent themes included “Power,” “Quality of Life,” and “Unstructured Activity.” This iterative process of coding and re-coding data facilitated the identification of thematic categories (and inconsistencies in the data) and ultimately allowed me to arrive at conclusions about what was going on in the culture and why (Thorne, 2000).

**Analytic Lens: Citizenship**

To further contextualize care within a broader socio-cultural and political framework, I adopted a citizenship lens. Consistent with my critical ethnographic approach, citizenship highlights questions of social justice by foregrounding the influences of socially ascribed categories on the experiences of persons with dementia (Bartlett & O’Connor, 2007), as well as on care staff. This perspective calls for persons with dementia to be considered citizens who should enjoy access to the same rights as other members of society and strives to shed light on practices that lead to their
dehumanization and social exclusion (Bartlett & O’Connor, 2007, 2010; Brannelly, 2011). This theoretical concept helped me to identify and interpret how issues of citizenship were, or were not, influencing the day-to-day life of residents and staff. This perspective compelled me to focus on issues of social power, difference, and issues of autonomy and enfranchisement as they emerged in the data.

That citizenship can be extended to personal narratives/life histories though the concept of narrative citizenship was also pivotal to analysis. The linking of the personal and the political (Baldwin, 2008) through social in/exclusion and performative narrative practice/biography represented a key perspective from which I understood care practice at Cedar Grove.

**Analytic Lens: Intersectionality**

Throughout my data generation and concurrent analysis, I worked toward an account that offers “thick description” (Geertz, 1973) of a LTRC organization. My goal has been to construct a vital “cultural portrait” (Creswell, 2007) of Cedar Grove, one that is cognizant of my own subjective gaze and respectful of the community.

Influenced by postmodern and feminist theory, data analysis was also guided by the literature on social location and intersectionality. Intersectionality is a term coined by Crenshaw (1989) that underpins critical research with the goals of social justice (Hankivsky & Cormier, 2009; McCall, 2005; Strega, 2005). It is a perspective that is grounded in reflexive orientation and as such is crucial to this study. Postmodernism’s questioning of social identities as fixed or static categories separate from history has been instrumental in shifting focus to the ways in which social categories are multiple and overlapping, and socially constructed (Ramazanoglu & Holland, 2002). According to
Hankivsky and Cormier (2009), “social categories intersect to create unique social
locations, and it is the intersection which is of concern” (p. 8) in this type of analysis.
This concept promotes the understanding of power relations as dynamic interactions,
helping to shed light on how social structural factors construct one another (Krekula,
2007). Within gerontology, intersectionality is an important concept because it represents
a means to help researchers to achieve a more critical focus while allowing studies to
become more inclusive of different types of social dynamics (Buch & Staller, 2007;
Dressel, Minkler, & Yan, 1997).

The lens of intersectionality guided the analysis in several ways. From the outset,
I considered socially constructed categories (age, health status, physical ability, gender,
race, class, sexual orientation) as they relate to the distribution of power, social structures
and participants’ experiences within Cedar Grove. This methodological decision might be
seen as an effort to extend insights into identity positions of particular relevance to older
women, broadening analyses beyond gender, race, and class (Anthias, 2012; Hulko,
2009). Next, I considered participants’ experiences of daily life in relation to his or her
intersecting social locations and attendant access to relative power within the culture.
Adopting an intersectional lens furthered my understandings of the complexities of the
broader socio-cultural context and people’s access to citizenship rights in which
individuals’ experiences of care and work were located (O’Connor et al., 2009). This
approach was useful in the creation of findings in the form of residents’ vignettes—
narrative representations of resident participants’ life in care.
Emerging themes were brought back to participants in interviews and conversations to help clarify my coding and understandings of salient themes. How this helped to add depth and credibility to my analysis will be developed below.

**DCM Interpretation**

To interpret the DCM data generated in this study I followed DCM guidelines, with an important modification. DCM sessions produce data using four coding frames (as detailed earlier) for interpretation. The first BCC coding frame records the behaviour (23 different types) in which the person with dementia is engaged for the time mapped. The second coding frame captures the well and ill-being (WIB) of the individual mapped during each 5-minute time frame. The WIB score is a quantitative measure revealing the percentage of the time frames that the individual (or group) was found to be in each different mood and engagement (ME) value. WIB values range in value from -5 to +5. This value records the mappers’ judgment on the quality of life and interaction experienced by the person with dementia (Innes, 2003). The third and fourth coding frame records information about care interactions that support or hinder the personhood of the resident. These are referred to as Personal Detractors (PD) and Personal Enhancers (PE) that occur during the session. I then used each of these coding frames in the analysis of the data to shed light on the quality of care interactions and social milieu that influences the well-being of the person(s) with dementia.

In its typical form, DCM involves two “mappers” observing and making qualitative notes on five residents’ experiences and activities over a representative time period (Sloane, Brooker, Douglass, Edelman, Fulton, Jarrott, Kasayka, Preisser, Williams, & Zimmerman, 2007). However, in this study, the reliability of my coding, that
is, my adherence to DCM operational rules, was supported through detailed qualitative notes I recorded during mapping sessions. These notes focused on the coding decisions I employed and gained more importance because in this study I was the “lone mapper” (Kelly, 2009). Detailed qualitative notes then were vital to providing key contextual information to ground interpretation.

Group data that illustrates the range of behaviours and the corresponding length of time the BCC was recorded (24 hours mapped) for residents of Holly Street is presented in Appendix D.

**Document Review and Discursive Practices**

My analysis of documents in this study was influenced by Foucault’s (1972) distinction between archaeological and genealogical methodologies. According to Foucault, archaeology is a method for analyzing statements (“discursive practices”) that occur in, for example, policy documents and medical records (Scheurich & McKenzie, 2005). The archaeological method looks at how discourse functions, rather than why it functions (Strega, 2005). An area of focus for this study was a review of the philosophical statements and policies within the facility, which were then compared with observational and interview data. I selected for review those documents that were referenced by culture members in various conversations or meetings around care provision. Genealogical work, on the other hand, is interested in the why of discursive practices (Foucault, 1972). This method also looks at statements in the historical record; however, genealogy includes an analysis of the relationship between power and knowledge in the present (Cook, 2005; Powell & Biggs, 2003; Scheurich & McKenzie, 2005). For gerontology, genealogy is valuable as a way of connecting official statements,
such as policy and procedure documents, to current concerns. I listed examples of documents in the organizations’ “historical archive” earlier in the chapter. I also accessed LTRC policy and report documents governing residential care in BC that were of relevance during fieldwork. Attention to discourse in these ways is vital to understanding power/knowledge relations in the culture, the discourses, terminology and dominant narratives that shaped the social milieu at Cedar Grove.

Through analysis, I was able to detect how and in what ways person-centred philosophies—for example, recognition of personhood or an emphasis on social inclusion—are reflected in culture members’ discursive practices, or in other words, have been integrated into the daily life of the people who live and work at Cedar Grove. It also served to highlight constraints on PCC philosophies within the various regulatory policies and procedures. This review is key to better understanding the research site, to ascertain the degree that Cedar Grove is a facility that creates the organizational conditions necessary for the PCC approach for which it appears to advocate. Another example of this analysis was a review of several residents’ electronic charts (e-charts) via GoldCare that facilitated my understandings of how care planning is impacted through the clinical framework of the Resident Assessment Instrument/Minimum Data Set (RAI/MDS) (Dellefield, 2007, 2008). In particular, I was interested in how e-charts influenced the documentation of access to, and use of, residents’ life histories in care practice.

Interpretation of the data generated through this method was also vital to my ability to contextualize incidents encountered in the field, tying these experiences to the broader social and political trends, and in so doing, support the quest of CE to elucidate taken-for-granted assumptions present in the culture under study (Madison, 2005).
Establishing Trustworthiness

Reflexivity

Within interpretive research practice, critical reflection on the research process also involves locating ourselves in the research. I considered the biases and presumptions I brought to this study throughout. Maxwell (2005), Finlay (2002) and others, identify researcher bias as a threat to a qualitative study’s validity. The imperative to state, from the outset, one’s biases in relation to the research focus is a significant challenge in qualitative inquiry, but one that is of paramount importance to this study in light of its conceptual framework. During fieldwork, I constantly encountered situations that challenged me to reflect on my ethnographic self (Coffey, 1999) and ultimately impacted the kind of data I generated, as well as its analysis.

The practice of reflexivity in qualitative inquiry has been defined as “thoughtful, conscious self-awareness” in which findings can be seen as negotiations between the research and the researched (Finlay, 2002, p. 532). Reflexivity draws on feminist principles of research and demands that I critically evaluate my role as a researcher in terms of the power dynamics at play while in the field (Buch & Stiller, 2007; Ramazanoglu & Holland, 2002). My work in the field and the integrity of this study rested on my awareness of the privileges associated both with my status as a member of a dominant social group or groups, a female researcher pursuing advanced education, and as a person not subject to discrimination based on age or cognitive ability. Reflexivity involves accountability for how knowledge is produced (Ramazanoglu & Holland, 2002). In traditional ethnographies, researchers are often positioned as strangers—as people who
enter previously unknown “fields” to learn about and report on “the Other” (Denzin & Lincoln, 2005, p. 1). Often, this type of ethnographic research involved Westerners travelling to remote parts of the world to study people of dissimilar backgrounds (Buch & Staller, 2007; Clifford, 1986). In early anthropological work, the process of integration into a culture is oftentimes described as a linear trajectory that begins with “strangeness” on one end, progressing toward the researcher’s familiarity and eventual “membership” in the culture at the other end, all-the-while maintaining a critical distance from which to interpret and analyze the culture under investigation (Coffey, 1999), lest one “go native” (Borbasi, Jackson, Wilkes, 2005, p. 497). More recent ethnographies investigate cultures closer to home—such as the nursing home—and challenge the validity of such claims of objectivity, otherness and integration and the notion that a study might end with the production of a “true” account of the culture under investigation.

A critical postmodern ethnography contests the absolute distinction between observer and observer, subject and object, seeing it instead as an “epistemological necessity” that “denies the self” of the ethnographer (Coffey, 1999, p. 21). The focus on reflexivity and exploring the role of the researcher in the process of knowledge creation, has been seen as a means of addressing the postcolonial (patriarchal) legacies of Western ethnography that claim objectivity and unbiased social science (Leibing & McLean, 2007). In the so-called “new ethnographies,” there is no agreed upon amount (or codified method) of reflexivity that one is expected to adopt or include in an ethnographic monograph (Coffey, 1999). Reflexivity is seen as a more fluid and contingent process that must be continuously negotiated by the researcher.
For me, this image of my own subject positioning was impacted by the experience of being in the field, and how in turn, I understood myself to impact those people who I studied alongside. As part of the departure from traditional ethnographies, those in which the boundaries between the self and other are fixed (Abu-Lughod, 1990), I have considered my position in the field through the act of reflexive memoing. In these memos I reflected on my experiences of the troubling boundaries between insider and an outsider-ness and the more general “complexities and relations of the field” (Coffey, 1999, p. 22).

*Power and Reflexivity in the Interview Process*

In this section I provide an example of how my reflexive approach impacted fieldwork and ultimately shaped this study in important ways.

The issue of reflexivity featured prominently in relation to interviews I conducted with residents. Although I had proposed interviewing residents who were at varying “stages” of dementia to obtain insights on the range of experiences at Cedar Grove (which would necessitate involvement of a proxy, such as a family member), this is not what I ended up doing. Like many researchers of dementia, having interviewed people with dementia across a range of abilities, I was confident going in that I would be able to engage people in a qualitative interview in which I would tap into descriptions offering “rich” quotes of what their experiences as residents of Cedar Grove entailed. Like other researchers focused on PCC, I consider the involvement of persons with dementia in the research process as a critical and underdeveloped part of dementia research, and I wanted to add to this limited area of inquiry. To build up my confidence for this aspect of data generation, I first approached those residents with whom I felt I enjoyed the best rapport.
I drew on my interview skills with this population to assist people to contribute to the study and hopefully to have a pleasant enough time doing so. After the first interview with an amazing woman who might be described as an ideal participant, I experienced a niggling feeling about this plan and wrote about it in my field notes.

I came to realize that there was the potential for the questions I asked to evoke negative emotions in residents and not something they could comfortably discuss. The crux of my discomfort in these interview situations was my realization that, for most residents, living in LTRC was not a positive choice. For many, if they had the option, they would be living at “home.” The formality of the traditional qualitative interview, even if it was conversational in tone and structure, elicited negative accounts and difficult emotions. The qualitative interview, “the quintessential data collection method” (Kirkevold & Bergland, 2007, p. 68), in this study seemed to lend itself to conversations that were markedly different than if I spoke with the same person informally. However, during informal exchanges, individuals often provided insightful comments about their experiences, their feelings and reactions, such as what they were looking forward to or what they had enjoyed that morning, as well as what they were unhappy about. In contrast, when I asked a person about their day in the context of the formal qualitative interview (i.e., consent given, recorder turned on, seated across from one another), they seemed more likely to answer in the negative. For example, they might tell me, “I didn’t do anything today” and other comments that conveyed their displeasure with their current living situation, and life. I was concerned about stirring up negative feelings in participants. More than this, as a qualitative researcher, I was interested in expanding ways to include the perspectives of persons with dementia in research; I felt it was
unethical to ignore participants’ negative reactions and proceed with the interview to more expeditiously access verbatim quotes. I was also interested in more meaningful responses that might represent a range of emotions and aspirations to inform practice. Certainly, when people shared experiences that conveyed hopelessness and despair, the impact on me was deeply troubling. Having stirred up these emotions in the person, I was left questioning my ability to uphold the ethical standards and interactions I was committed to in this study.

From a methodological perspective, this tension centred on my awareness of my position as a qualitative researcher and the drive to create situations where I could access rich, verbatim quotes that I could then use as “proof” of the resident participant’s assessment of care and my ethical relationship to the resident(s). Beyond paternalism or rapport even, there was a trust that I felt was bestowed on me by the people I encountered in the field. Engaging residents in a discussion that engendered negative feelings was a breach of that trust. It is important to note that I have conducted interviews in Special Care Units with people with advanced dementia that were based on life stories, that were reminiscence based, and that did not create these feelings in me and in my opinion (and that of family members), were positive encounters for the resident participant. In this study, a combination of the subject matter, the vulnerability of resident participants, and the context in which the interview took place impacted the interview process in unique ways. Therefore, getting to know residents (in particular) at Cedar Grove over time was crucial, and I made the methodological decision to formally interview fewer residents than I had anticipated. Instead, I decided to spend more time in participant observation, chatting and observing in order to learn from residents through their daily engagement
with their social world the ways in which their social environment could be made better for them.

It was not only the subject and living circumstances of the resident, but also the power dynamics inherent in the formal interview itself that elicited these responses. As the literature suggests, in the interview context, I as the researcher had power and the resident participant was comparatively powerless. This dynamic is magnified when interviewing a person with a more advanced dementia. In contrast, when the two of us were sitting side-by-side in the common area, chatting or walking around, the differences between us were leveled and I was able to learn “answers” to my questions in a more mutually agreeable manner. Results that were gleaned in these informal situations were no less valuable to my study than if I had recorded their comments. I surmised that the resident participant was empowered to speak their mind and share insights in a more equitable, less threatening manner.

**Positionality in the Field**

Critical ethnography seeks to elucidate cultural and societal power dynamics that impact participants while remaining cognizant of the power and privilege that researchers bring to the field and which occur in the research process (Madison, 2005). Thus, I have endeavoured to the best of my ability to foreground and think through my own positioning and influence within the research site.

Although I was unknown in the research site, dementia care was not a new field to me. However, what set me apart and made me self-conscious of my presence at Cedar Grove was my relatively new status as a graduate student. I was not an employee or programmer, or a research assistant, as I had been in the past, but someone who was
committed to an academic process and subject to extrinsic interests. An example of the impact of my position in the field occurred in the early part of my fieldwork and involved my use of a small hand-held computer to record field notes, jottings and initial insights. My use of the computer while in the staff spaces or common areas attracted attention from staff. Specifically, the computer evoked informal discussions around the use of email and the Internet and from these chats I discovered that computer use (for work and leisure) was not a part of many staff members’ daily life. Of course there were many members of staff, mainly nursing staff and administrators who relied on computers to do their work. However, I soon learned vital information about staff roles and computer use in practice and the perception among many direct carers of a lack of access and necessary skill set for computer use. My use of the computer for field notes while on site, regardless of how I tried to be inconspicuous, garnered attention, and I felt it was a gesture of power relations. Because of this, early on in fieldwork, I decided to leave my laptop at home and to use a paper notebook, and I would later transcribe jottings or notes from the field into a computer at home. This also allowed me to clarify and elaborate on initial thoughts.

In the quest to discover what residents “did” day-to-day and which aspects of their day generated the most meaning for them, I found it difficult to remain a neutral or ‘outside” observer. Faced with the interests and needs of residents and the opportunity for personal connection, I was challenged to maintain critical distance in this study. I have a background in activity programming, so it is not surprising that the quotidian activity of persons with dementia in residential care was a primary interest of mine going into this study. I wanted to know how and in what ways a philosophy of care that had the “person” at its centre constructed daily life for residents. From the outset, I understood that this
was not a straightforward proposition and could not easily be determined through solely objective techniques of observation and structured interviews, but would involve subjective investment in the social space of the facility. If I wanted to gain access to the most difficult questions around the experience of LTRC living, I would need to find ways to challenge my reflexive self in one area in particular. Whereas many of my interactions with those at Cedar Grove were rooted in my not knowing and wanting to understand, when it came to assessing and describing the quotidian struggles of the resident population I felt I did have knowledge and experience that I struggled with in this new research environment. With more that 15 years of working with older adults and professional experience in variety of institutional care settings, I saw myself as less of a curious student researcher and more of an insider to the larger care community.

My self-positioning in this study impacted data generation in significant ways. For instance, given my experience and ethical relationship to the subject matter, at almost every PO session I conducted, I struggled to control my urge to “interfere” with the social environment. Namely, when I was in the common area of the SCU and nothing was going on—those times in-between structured activities, care, or meals, especially in the evenings or on weekends— it was nearly impossible for me not to interve nue or otherwise engage with residents. Entering common areas at these times, I noticed the conspicuous absence of any kind of activity. This would impact me at a visceral level, and I could not ignore the impact of this void on the people there. It was painful to resist the desire to open blinds, turn on music, turn lights on or off, make tea, or grab a paper or a picture book to engage a resident or two in conversation, and at times I did “interfere.” I also encountered strong discomfort discussing social care, particularly during interviews with
direct carers. I felt a need to hedge around the topic in informal discussions and in formal interviews, and whenever possible I tried to allow participants to raise the topic first. When this did not happen, I would tentatively raise the subject. The need to guard my words and to resist commenting on resident disengagement was less the case in my interactions with administrators, with whom I occupied more similar social locations. Because of my professional experience and academic affiliation, I found that issues of social privilege, inequality, and power dynamics were less of a concern in these relationships and because of this I was more able to share my insights and learn from others.

I came to be acutely aware of the frustrations many members of the culture encountered on a daily basis. The question of meeting the social needs of residents and the meaning attached to them were intertwined with micro or intra-institutional positions and stakeholders. From the ethnographic literature, I understand these struggles to be representative of the negotiation between what traditional ethnographers have presented as a binary separating insider/outsider in the context fieldwork. Also, although I had read about the role of the ethnographer entailing a process of development along a participant-observer continuum, and so expected more or less a linear path in this regard, this is not what I found. Instead, my relationship to these categories changed and fluctuated, depending on context. I wrote about the multiple identities and the fluidity of insiderness/outsiderness I experienced in the field as challenges and opportunities in reflexive memos throughout fieldwork.

Importantly, I did not (and do not) want this study to discount the work of a dedicated team of individuals who faced many challenges, on many fronts, providing
care. I found I struggled with how to be critical without being seen to be judgmental, i.e., without leveling blame at individuals or particular caring roles. The last thing I wanted was for my study to be interpreted as admonishing direct carers, or to have the outcome of my study adding to their already over-burdened workload.

I also battled with the preconceived notions that I brought to this study around conventional approaches to activity for older adults, in particular, my largely negative impression of “traditional” activity programs in LTRC. These are the type of programs where numbers of attendees, completion of checklists, and an attractive schedule take priority over a resident’s actual engagement. I went into this study with the notion that standard leisure programming is largely ill-suited and unable to meet the needs of residents with dementia vis-à-vis meaningful activity and social engagement. However, as with other aspects of life in this culture, things were more complicated than they initially appeared, and I forced myself to challenge key assumptions and beliefs. In critical inquiry – where the influences of beliefs are acknowledged rather than cast aside—this stance helped me to describe and interpret the dynamics at play in the culture and to confront my own biases.

During the various meetings, care conferences, and staff gatherings I attended throughout fieldwork, my primary role was as a student researcher, an “outsider,” and a person who was supposed to be on site to observe and not participate. However, at these times, I was particularly conscious of the multiple identities I experienced and was granted in the field. During meetings, I was often introduced as a student researcher, and while very appreciative of the opportunity to attend and to observe the language, attitudes, behaviour, and experiences of the organizational culture of Cedar Grove, I
struggled to maintain my student neutrality. There were times when I remained silent even though I felt I might have something to contribute to the group on a given topic. On occasion, I did ask questions, but often felt the need to check myself not to interject my observations or opinions into these gatherings. Instead, I used these opportunities as a vehicle to increase my understandings of the care culture and the broader LTRC context and I recorded my thoughts in my notebook to store them for later. These moments of silence and misgivings provided important opportunities to generate and focus data; my thoughts were included in my field notes, memos, and eventually, they were reflected in questions for future conversations, both formal and informal, with culture members.

Through the process of finding my place in the Cedar Grove culture, I wrote field notes about my experiences managing “strangeness,” about the challenges of the complex relations that I encountered and was a part of. In turn, these reflexive memos informed key parts of my analyses. As is consistent with postmodern epistemology, my reflexive memos, and the practice of recording my personal reactions to participants’ narratives (Creswell, 2007), helped to remind me to consider my positionality or the intersectionality that produced it. As Madison (2005) asserts, a focus on positionality in critical ethnography is “vital because it forces us to acknowledge our own power, privilege, and biases just as we are denouncing the power structures that surround our subjects” (p. 7). It also helped me to sharpen my analysis of the data and to focus on aspects of the culture that I would not have otherwise been able to recognize as being crucial to it and/or my study. I worked at maintaining awareness of the privileges associated with my fluid status and multiple social locations and of the potential impact of these factors on data analysis and ultimately, findings (McCorkel & Myers, 2003).
Reciprocity in the Field

Fundamental to a critical approach and connected with this study’s ethical considerations is the notion of reciprocity (Creswell, 2007). Critical ethnographers do not seek to build rapport and trust with participants without considerations of the potential impact on those involved in the research. The feminist method of looking for opportunity to “give back” to the participant community was an important component of this critical ethnography. At the proposal stage, I was uncertain what this contribution might look like. When, during my fieldwork, leadership decided to embark on a series of facility-wide staff group meetings aimed at culture change and moving practice forward I was presented with a rare and unanticipated invitation to “give back” or contribute my research to constituents. This opportunity is also consistent with critical ethnography and its focus on developing a flexible, iterative methodology, where there is a continual back and forth between data generation and analysis (Buch & Staller, 2007).

In addition to the group meetings, near the end of my fieldwork, I was afforded the opportunity to share emerging findings and analyses with the board and executive and with the medical advisory committee. These two occasions gave me a chance to interact with a very different aspect of Cedar Grove’s culture of care, but one that has significant institutional power or influence. I participated in these events because I felt they might facilitate a dialectic relationship connecting theory and praxis (Ray, 1996).

I also saw my presentations to these groups as opportunities to create knowledge that uses theory to produce knowledge of practical relevance to the research site (Madison, 2005). The quest to involve participants toward (at least in some measure) the co-creation of findings was in keeping with this study’s conceptual framework. This type
of participant engagement is significant in critical ethnography that endeavours to produce knowledge that, as Jordan and Yeoman’s (1995) state, makes a difference in the lives of participants:

Rather than providing expert knowledge, the role of the critical ethnographer should be oriented to facilitating the production and dissemination of really useful knowledge within the research site.

(p. 401)

That emerging findings from this study were used by Cedar Grove to help translate knowledge to practice by way of staff education is a testament to the contribution of this study’s findings to the research site, and hence, significant in this discussion of trustworthiness. These group meetings—those with frontline staff and those with the executive and advisory—were instrumental in the co-production of knowledge around person-centred care practice. Data generated through these events (field notes, evaluation forms of the presentation) and the active collaboration of participants (Buch & Staller, 2007) supported key insights into knowledge mobilization/integration in dementia care practice.

**Representation and Voice**

In traditional ethnographies, the ethnographer’s voice dominates and the subjects of the inquiry, the “‘othered’ people” are “analysed at the level of meaning, social structure, power relations and history” (Lather, 2007, p. 481). This question of cultural representation was at the heart of a “crisis of representation” (1986-1990) that changed North American qualitative research (Denzin & Lincoln, 2005, p. 3). That is, following ethnography’s “Fourth Moment,” we saw, for example, the erosion of belief in
objectivism and anthropological notions of fixed cultures and positivist notions of reality and “truth” (Denzin & Lincoln, 2005; Merriam, Johnson-Bailey, Lee, Kee, Ntseane, Muhamad, 2001). Contemporary ethnographies involve a critical interpretive stance that incorporates the voices of those who participate in both the research process and the ethnographic text. This research creates what have been described as “messy texts” (Coffey, 1999). In part, this messiness stems from issues of voice and representation. In this study, voice is considered in relation to the researcher and participants. Firstly, my voice as the researcher appears via a reflexive approach that, as I have discussed, accounts for my position in relation to the study and also for the decisions I made with respect to data generation and analysis. Secondly, a central concern of this investigation relates to voice vis-à-vis study participants. By employing reflexive research methods, the tendency to silence marginalized groups is addressed by exploring both how and in what ways voices might be constrained, and correspondingly, which are heard. As the author of this account, I am responsible for deciding how and which voices are represented and remain in a powerful position (Ramazanoglu & Holland, 2002). Attention to which aspects of the data set and whose stories are told are in keeping with epistemological and ontological underpinnings of non-positivistic paradigms. As Mantzoukas (2004) contends, the qualitative researcher is responsible for “whose voice is louder” (p. 1002).

To the best of my ability, I have sought to ground the trustworthiness of analyses and findings by foregrounding the voices of participants, which were accessed through the multiple methods employed in this study. Graham (2010) asserts that ethnography has a unique capacity to challenge normative assumptions about aging because it enables
older people, often subjected to decontextualized methods like experiments and surveys, the ability to exercise their own voice. This facility might be considered even more important in the context of dementia. Notwithstanding their distinct nature, participants’ voices and their experiences of daily life at Cedar Grove are rooted in wider socio-political structures they are embedded in and, as such, their voices might be understood to speak for others, similarly marginalized in the wider LTRC milieu in Canada.

I attempted to incorporate the voice of participants in this study in three main ways:

1. Through verbatim quotes, I have sought to ground analysis in the data generated from conversations and interactions with carers, residents and their families.

2. Sharing observations and insights gained by shadowing carers as they went about their daily work. For example, I witnessed how a Hoyer lift is operated by an RCA, or how care routines assisting residents to get ready for the day, and this allowed me to appreciate the skills and competencies in a way that does not privilege conventional ethnographic methods such as the interview and instead foregrounds embodied skills and non-verbal expressions of self by care staff.

3. Accessing and documenting the experiences of the most marginalized members of the research site, those with moderate to advanced dementia through the methods of Participant Observation and Dementia Care Mapping. Although not without limitations, it allowed me to add significant insights into analyses and awareness of residents’ affective
bodily communications and engagement with the world around them as well as embodied care practices.

**Ethical Concerns**

A concern for ethics was foundational to this investigation. Tinney (2008) warns that conducting ethnography in an institutional setting has inherent ethical considerations, which are magnified when dealing with vulnerable populations living in a nursing home. Indeed, ethical issues such as confidentiality, privacy, gaining consent, and the recognition of the multiple relations of power informed every phase of this research project. Some of the methods that facilitated my immersion in the LTRC culture carried with them what has been described by others as the legacies of anthropological practices that are deeply connected to colonialism and imperialism (see for example, Jordan & Yeomans, 1995). For example, ethnographic observation in a research site has the propensity to induce unease and discomfort in those who are the focus of the researcher gaze. In this study, the use of the observational tool DCM might be seen to magnify these feelings in those under observation.

To mitigate the feelings of otherness (Othering) that these methods might engender, I reminded participants prior to observation sessions that the purpose of the study was not to evaluate their work performance and that they may choose not to participate. As noted earlier, the presentation of this study in formal and informal meetings at various times throughout fieldwork helped to address participants’ concerns and was a key part of its ethical approach. For both staff and residents, I responded to questions during mapping sessions and was sensitive to participants’ reactions throughout that might have led me to stop the mapping session. Following DCM guidelines, when
this type of interaction occurred while mapping I noted the interaction on the time-frame and this information was then excluded from the DCM maps.

Although Cedar Grove was not an alien culture to me, and I was not a complete outsider to organizations that offer LTRC, nor was I an “insider.” Many researchers in the field have chosen to study where they worked. I think it is important to note, however, that I was not a paid employee of the culture under investigation and because of this I did not face the ethical quandaries or difficult work-based power relations. When I recruited staff, I was confident that those who agreed to participate did so from a desire to contribute and not because they were worried about my power over them or potential for any direct retribution on the job. I should also note that when I worked in the field, I was a member of the Hospital Employees Union, the union that represented RCAs and leisure staff, the largest portion of the employees at Cedar Grove. By the time I began this study, however, I was no longer a member and had no direct connection to the organization or its representatives so it is doubtful that this exerted any influence.

My initial period of immersion leading up to the first interview took longer than I anticipated, from my study of published material. Because I was not an employee at the research site I had to build a field identity more or less from the ground up. Given the range of possible roles within the PO method, from neutral observer, to engaged participant, I adopted the role of observer; this allowed me the time to feel comfortable with and become familiar to the community. This initial period of inquiry was also necessary from an ethical perspective, in the sense that it allowed me to achieve recognition within the facility and connection with members of the broader care culture before moving into a more active role. As a student researcher, I sensed that I had to
establish a sufficient level of rapport and trust prior to approaching potential participants. Critically, this time also allowed me to build confidence in my ability to converse about the organization from a degree of empirical knowledge, which in turn facilitated recruitment and conceptual depth in ensuing interviews. Practically, this meant that I did not conduct my first interview until the 22nd PO session. By the time I began my first DCM session, I was familiar with most staff and residents (I did not conduct DCM sessions until the 29th PO session, or approximately 100 hours).

Ever mindful of the ethical considerations that this study entailed, I felt DCM posed significant challenges. As Brooker (2003) points out, although Kitwood and Bredin’s initial tool was “rooted in an ethical framework of person-centred care that promotes the well-being of people with dementia, their families, and their care workers” (p. 148), DCM’s evolution and widespread use internationally calls for diligence around its use and dissemination of findings. These considerations hinge of the fact that although DCM is valued as a method to explore the experiences of daily life and care of a segment of the resident population whose perspectives are rarely sought and a challenge to access, the tool posed two ethical challenges. First, my awareness and desire to mitigate my “researcher’s gaze” was severely challenged when mapping, despite the measures I took to decrease this possibility, such as undertaking shorter sessions and attempting to maintain a high degree of transparency in my process. A second ethical concern relates to informed consent. As with PO sessions generally, some members of the community had the ability to opt out of the observation sessions while others might not—those with advanced dementia in particular.
From a critical perspective, although DCM has evolved to address care practice at an organizational rather than solely individual level, as critiques of PCC and personhood have highlighted, DCM also lacks an ability to focus on broader socio-political forces that impact care on the ground. My decision to use DCM was based on its strength (and ability to address this study’s research questions) as an observational tool to evaluate the extent of a person-centred approach in a care setting, and more specifically, to generate data about the day to day lives of people with dementia who are greatly challenged to share their experiences through other methods of qualitative inquiry.

Maintaining confidentiality was another key ethical concern. Because this study focused on one research site, the potential for individuals to be identified in the data was greater than if I had studied multiple sites. Therefore, aside from reminding people that they were free to withdraw at any time, I also made use of pseudonyms in all textual data. Writing up this study, I used broad categories to describe participants (e.g., “direct carers” or “administrators”) rather than relating people’s stories and experiences to his or her specific staff role. This was less of a concern with Resident Care Aides, given their relatively large numbers on the care team.

Study Limitations

There were several methodological limitations to this study. First, there were those limitations inherent in any ethnographic research design, some of which have already been touched on. The challenge of conducting research in a space of marginalized people in ways that result in findings that reflect their experiences and that might make a difference is significant. The flows of power underpinning relations between the researcher and the researched also presented key hurdles. For instance, throughout
fieldwork, I sought whenever possible to blur the division between myself and participants, preferring instead to see us all as “subjects” of the research. However, with care staff in particular, the fact was that my questions could and did contribute to feelings of unease that highlighted our differences. It was clear that the decision to participate was not without some perceived risk to the participants’ well-being. It is probable that because of this, participants withheld information, resulting in a discussion that was mediated by the workplace environment and the tensions therein, even when I thought or hoped I had ethically mitigated the risk involved.

The second key study limitation relates to participation and recruitment. My ability to address difference in the resident population with respect to language, culture and gender was reduced in a number of ways. My ability to include the perspectives of non-English speaking residents, whose experiences of care would be markedly different than that of residents from the dominant culture that speaks a common language. On top of this, this goal was limited by the researcher’s own cultural position and the fact that I speak only English. It is important to note that the pool of residents I had to choose from was of limited cultural diversity. This profile is constantly changing and will with time come to better reflect the cultural diversity of the city and nation. A lack of male residents in the sample also meant that their voices are largely absent from this study.

To an extent the study sample reflected my own field identity. How I was able to position myself along, for example, lines of class, gender and age, played a key part in my ability to recruit participants and the experiences I had in the field. The fact that this is a doctoral research project meant that this aspect of my identity was always, necessarily, at the forefront of my interactions with participants. Similarly, my use of the
process consent method meant that an awareness of the primacy of my research project was always present thus impacting a more “naturalistic” approach to the setting.

Difficulties in recruiting family members to participate in this study also limited my ability to include the perspectives of these key stakeholders in long-term care in general and person-centred approaches specifically.
CHAPTER 5:
THE SOCIAL WORLD OF CEDAR GROVE: RESIDENT VIGNETTES

In this chapter, I present findings in the form of vignettes based on seven people who live in the two sites of Cedar Grove—Holly Street, the facility’s special care unit and Juniper Way, a “usual” floor. These vignettes are offered: 1) to help readers obtain a sense of the people who live at Cedar Grove; 2) to be able to ground findings and issues of practice in the lives of members of the culture of care under study; and 3) to help develop the everyday care context. Taken as a whole, residents’ insights—experiences and the meanings they attached to them—are vital in helping researchers to create a detailed picture of the social world that these individuals inhabit and help construct.

My use of these vignettes is informed by critical ethnographic practice in that they represent an alternative to other assumed fact-based methods of reporting. Coffey (1999) states that the “practice of ethnography relies upon the exchange of lives, selves and voices. It is about personal communication, face-to-face interactions and encounters. And it is then about the writing and representing of these” (p. 130). She goes on to say that although how we tell the stories of the individual and collective is not straightforward, that through “fieldwork and our representations of it, we are engaged in the construction of the lives of others” (Coffey, 1999, p. 130).

In this spirit, these vignettes represent a compilation of material derived from the various data sources generated in this study, including field notes and transcripts created during individual interviews as well as during PO sessions and, in some cases, DCM sessions. In putting these accounts together, I have combined reflections and insights
from these sources to help to tell the stories of the residents who I met at Cedar Grove and whose direct involvement has dramatically shaped and focused my fieldwork. These vignettes are also an attempt to include the voices of a population who are often absent from research. This is vital because at some point in the course of dementia an individual might well (literally) have no voice. My ability to “give voice” to a marginalized population, a hallmark of critical inquiry, takes on a new meaning when the cultural lives one attempts to represent are people with dementia who make their experiences known often through affect and non-verbal gestures—forms of communication that do not lend themselves to verbatim quotes, commonly considered a hallmark of good qualitative research.

These seven vignettes then attempt to portray the individuals (Emilia, Fran, Hazel, Eva, Hannah, Ruth, and Maria) behind the data while providing key references points, helping to ensure that it is their stories that both provide its impetus and frame this ethnographic investigation. With this in mind, I should note that because of the varying levels of dementia impacting residents that some of their stories were easier to access and construct than others. For example, Eva’s story was perhaps most difficult to access due to the communication challenges associated with her dementia that prevented conversations or interviews and a shortage of familial involvement: Hence, much of her vignette is constructed from PO and DCM data. Spalding and Phillips (2007) comment on the trustworthiness of vignettes and state, “like all other forms of data collection, analysis, and representation,” these can provide “a mediated account of the ‘truth’” (p. 961).
Holly Street: Emilia, Fran, Hazel and Eva

Within the Cedar Grove campus of care, Holly Street is the special care unit (SCU) for residents. Residents of this floor are more likely to have advanced dementia. Unlike the other care floors, Holly Street is a secure floor, and so people who live there are restricted in their ability to independently leave the floor. In general, residents dine and participate in leisure programs in the common area. This floor also has a large terrace with raised beds with plants, flowers, herbs, and vegetables for residents to enjoy. Many of the people on Holly Street are mobile and spend a lot of time walking. Others rely on wheelchairs and require staff support in many aspects of their daily life. The following are vignettes of four residents of this floor: Emilia, Fran, Hazel and Eva.

Emilia. Emilia was an attractive person in every sense of the word. Perhaps the first thing one noticed was her independent streak, which was both a help and hindrance to her life at Cedar Grove. Physically, she was quite independent and needed minimal help to dress or bathe. She was a tall, slender woman with short, graying hair and a flare for clothing. Emilia loved art, and in her room there were paintings—some that she had painted and others that she had collected in her travels.

Born on the East Coast of Canada, the second daughter of five, Emilia moved to the West Coast in her early 20’s. She worked for many years in a job that she took pride in; she was a personal assistant to a provincial politician. Always an adventurous type, she enjoyed a comfortable retirement that included travels abroad and to other parts of the country and the United States to visit her geographically dispersed family. Emilia did not
marry and had no children. She did enjoy a warm relationship with a niece; Freda was her only relative who lived nearby and who was greatly involved in Emilia’s life.

Now in her late 80’s, Emilia had lived on Holly Street for two years. Before that, she lived for almost a year on Juniper Way. Her move to the SCU was precipitated by a combination of her mobility status, her independent nature, and her desire to go outdoors. Specifically, she loved to walk outdoors and struggled with the restrictions placed on her on the secure floor; she often felt trapped. Prior to her series of strokes and a diagnosis of vascular dementia that resulted in her initial move to the facility, Emilia had lived for over 50 years in the local vicinity, so she knew the area well. She wanted to be outside and to walk in the places she had known for most of her life, yet her increasing confusion and inability to speak coherently put her at significant risk if she was to go outside on her own.

Problems began when Emilia started to remove her security bracelet and then leave the facility. Following many successful attempts to leave the building, several which involved the police locating her and returning her to Cedar Grove, the decision was made that in the interests of her safety, Emilia should move to the SCU. Another factor in this decision surrounded Emilia’s reluctance to eat her meals in the main dining area. Evidently she was self-conscious about her aphasia and did not like to interact with other residents over a meal served in the large dining room on the main floor. Emilia had taken to eating alone in her room. She had lost weight and was increasingly isolated.

Her niece Freda was involved in the decision-making that surrounded Emilia’s changing care needs. At a care conference, the suggestion for Emilia to move to the SCU (where residents live and dine on the same floor) was raised, and at first Freda rejected
the idea because she did not like the idea of her dear aunt being “locked up.” However, once staff gave Freda a tour of Holly Street, she came to the conclusion that her aunt would be able to enjoy the large outdoor terrace and that she would be safe, so she agreed to the move. For her part, Emilia, always an adaptable person, transitioned easily into life on Holly Street. Although her hearing and speech made it difficult for her to communicate verbally, she was able to convey to Freda that she understood and accepted that the move had taken place: “This is where I am now,” she clearly told her niece. To help her aunt settle in on the SCU, Freda brought in additional artwork and photographs from home, and the dresser, her favourite reading chair, and knick-knacks were brought from her other room. With the help of her niece, Emilia’s new space was made to feel welcoming and homey.

On Holly Street, Emilia became a staff favourite. She required minimal support to meet her personal care needs and she was bright, fun loving, and relatively independent. She participated actively in many of the floor’s activities: the music programs, weekly services in the chapel, and the various parties that occurred in the common area. However, because of her communication challenges, her niece was concerned that her aunt was still oftentimes alone with too much time on her hands. To address this, Freda visited often, which was difficult because she worked and lived a significant distance from the facility. However, she said that once she made the effort, she never regretted the time she spent with her aunt. Sometimes Freda and Emilia’s visits took place in Emilia’s room or the two joined in scheduled activities. According to Freda, Emilia’s preference was always to leave the facility—to go out in the car, to get something to eat or to go window-shopping on a downtown street.
Because she had the opportunity to see her aunt in a different environment, Freda was often surprised at what her aunt could do and the (negative) impact that the facility environment was having on her aunt’s independence. For example, Emilia would choose fruit from the grocery store and purchase it herself, something Freda thought staff would be surprised her aunt was capable of. Similarly, Freda did not like it when she once observed her aunt being escorted to a bath without staff declaring their intentions.

These were minor things to Freda because she considered staff to be caring and hard working; she was reluctant to pass on her negative comments. However, she said that the staff members’ failure (or what she perceived to be a failure) to consider Emilia’s retained skills, “rubbed [her] the wrong way.” Freda felt that her aunt resented these gestures. This was an important area that was overlooked. Indeed Freda’s account of the situation echoed my first encounter with Emilia during fieldwork when I found her wandering around the halls mid-morning, carrying an empty mug. No coffee was available on the floor and when I asked her if she wanted coffee she nodded her head vigorously. When I returned to the floor with a coffee from the main kitchen Emilia was grateful; she then found a newspaper and sat down to enjoy her coffee and paper at a dining table in the common area of the SCU. Following this small intervention, Emilia was content to be on her own.

Fran. Fran struggled to be happy at Cedar Grove. During the time I knew her Fran was almost always walking. She presented as a petite, wiry woman with a lot of bright gray hair cut in a bob who wore wire-rimmed glasses that frequently went missing. Fran had
come to live at Cedar Grove three years prior to my study. She had been diagnosed with 
Alzheimer disease after several years of declining memory and increasing confusion.

Fran had little external support. Her husband had passed away long ago and her 
two children had busy lives led elsewhere in the province. Her family was small and had 
grown still smaller in recent years, so she had few family members or friends to advocate 
for her. A daughter who lived in northern BC had facilitated her move to Cedar Grove, 
but was unable to make regular visits.

Before moving to the SCU, Fran lived on another floor of the facility for two 
years; however, when her failing memory and behavioural challenges exceeded that 
floor’s care capacity, she was moved to Holly Street. Being restricted in the SCU was 
difficult for Fran, because she was a social person and liked to mix with a variety of 
people. Nevertheless she remained very active on the floor. Often, she was hand-in-hand 
with another resident, Gerta, the two moving in and out of the dining room, up and down 
the halls. Because Gerta had lost her ability to communicate in English, the two friends 
could not speak with each other. They communicated instead through gestures and 
physical affection. They were good friends. Fran loved to dance at parties, particularly 
with a male volunteer. She couldn’t talk very well by the time I met her, but she could 
effectively communicate using non-verbal forms of communication such as facial 
expressions, smiles and hugs, as well as the occasional two or three word phrase. Her 
smile was magnetic.

One day, as I walked down the hall toward the common area, Fran waved hello to 
me and then carried on her way, holding hands with Gerta. On another day during 
fieldwork I spent a lot of time with Fran and was able to more fully appreciate her
warmth and abilities. The music was on and bright daylight was flooding into the room and several residents were scattered at the various tables in the room, each at various levels of attentiveness, but not much was happening. Soon Fran and Gerta re-entered the common area, looking around the room to see what was going on. Witnessing this, I picked up a knitting basket and asked Fran if she felt like knitting. Her face beamed in response to the question. Fran and I sat side-by-side in the high-back chairs. Fran chose the bright blue yarn and after a couple of failed attempts, she proceeded to knit. I was amazed at the speed with which Fran recovered and was able to complete a knit stitch, then a row, and then many rows. I guessed that she had been a highly accomplished knitter. She often wore a mauve-coloured wool cardigan with complicated cables and enviable seams. On the occasions when Fran wore this sweater, I would compliment her on it, which delighted her.

On this day, Fran and I were united in knitting. She held the needles and wrapped the yarn around her hand as a knitter does. We communicated over the success or failure of a stitch. I also encouraged her verbally: “perfect stitch Fran,” “excellent work.” She was obviously proud and told me one time, very clearly, “I love this.” Hearing this, I was overcome with emotion. This is one of the few times I heard Fran utter a coherent phrase. The only other time I witnessed her speaking as clearly and with excitement was in response to the cat that lived on Holly Street during the early part of my fieldwork; Fran would say, “Isn’t he lovely?” and utter other words to that effect while petting him. Other than that, Fran’s aphasia was such that her verbal communications were difficult to decipher. While knitting, she occasionally said a few words in such a way that I understood them to mean that she was commenting on the activity and happy with her
progress. Mostly though, while she knitted with me, Fran was quiet, absorbed in her task.

Aside from the personal rewards that Fran seemed to gain from knitting, her embodied skill was also a possible source of pride. While she was knitting, she demonstrated to those around her that she could do something. Several staff came over to watch her and encouraged her in her work. Fran knit with me beside her for 40 minutes. She kept at it for another 5 or 6 minutes on her own, after I stepped back to see if she might continue without support. I found it remarkable that, given the advanced stages of her dementia, she could stay focused and sustain involvement in this activity for this length of time. After we had been together for about 45 minutes, something interrupted her and she stopped. However, before getting up, she rolled up the ball of yarn and the piece in progress in a way that suggested that this was the manner in which she had always left an ongoing project and then walked away.

Toward the end of my fieldwork, Fran had to use a medical recliner. She experienced several falls and had broken a hip that had left her unable to walk independently. Nevertheless, Fran remained a bright spark, with a big smile and a longing to connect with others. Revealing to me her continued desire to remain a part of what Hubbard, Cook, Tester, Downs (2002) refer to as “the communicative world,” when you entered her sightline, Fran would lock eyes with you and motion for you to come over and engage with her, exuding warmth by repeatedly kissing your hand. At the Christmas party I watched Fran from across the room and saw her moving her arms around in time with the music, grinning ear to ear, clearly enjoying herself.
**Hazel.** Hazel was an energetic woman who loved to read, dance, and go for walks outdoors. Of the people I met on Holly Street, Hazel was the most expressive and articulate in her disdain for her living situation. Hazel came to Canada following the Second World War, yet her ties to Scotland remained strong. Long retired from her clerical position that enabled her to enjoy a comfortable retirement, Hazel would refer to her working years as a great time in her life. Hazel was very particular about what she wore. She liked nice clothes and would comment on whether she liked what others wore, or not. She described herself as “career woman,” and said that her life took a different route than the usual wife and mother trajectory. Her family was small and distant, which meant that in her later life she relied on friends to help her. One friend, Sue, facilitated Hazel’s move into Cedar Grove, and she continued to participate in Hazel’s care planning.

When I first encountered Hazel, she had been diagnosed with vascular dementia. As a result of her disease, Hazel’s lucidity fluctuated dramatically and she was at times extremely frustrated. At one point she described feeling like she had a “veil” over her eyes that she could not remove. At other times she was confused as to where she was, and why. During these times she would express anger at the “people who put her” there. This was very upsetting to her. On one occasion when Hazel was particularly upset, a nurse took her aside and together they went over her chart that detailed the particulars of her history and how and why she ended up living at Cedar Grove. The impact of this at the time was that Hazel felt reassured by the information and she became noticeably calmer.

Hazel was the only resident that I met on Holly Street who I saw demonstrating the ability and/or inclination to read independently in her room. However, despite her
independence, Hazel was frequently distraught and angry. She was very vocal in her protestations. Her behaviour was largely seen as challenging for staff. The following early morning exchange was a typical interaction with her at that time:

   EK: Good morning Hazel.
   Hazel: No.
   EK: Did you not sleep well?
   Hazel: No, it's...I'm nothing. Not a person. Just something to be pushed around.

Hazel’s comment here reflected her overall perception that she felt her opinions did not matter; she felt that she was “done to” and not a participant in her everyday life. These types of comments troubled staff because they felt some responsibility for her unhappiness. Although they tried to encourage Hazel to engage in activities they knew she enjoyed, there was a lot of downtime that she spent brooding.

   There were times when Hazel seemed more at peace and even somewhat happy at Cedar Grove. For example, she loved to dance and music had obviously been a big part of her life: she was familiar with the lyrics and melody of many songs. Watching her participate in the music program or parties provided some of the few opportunities I had a glimpse of Hazel as a happy and engaged woman.

   Perhaps because she was often very negative and angry, care staff vocalized concern over Hazel’s behaviour and depressive state. They wanted to do something to help and since they knew Hazel had always enjoyed walking, in consultation with her friend, arrangements were made to hire a private companion to accompany her on trips outside. Hazel had the financial means to allow for this additional care. This addition to her care improved her mood and toward the end of fieldwork Hazel had a private
companion for several hours a day, seven-days a week. I would often see her with a companion in the main dining area and outside the building, coming to or from a walk in the neighbourhood. At these times, Hazel seemed uncharacteristically content and happy, in stark contrast to her behaviour when she felt confined and frustrated by her life on the SCU.

**Eva.** Eva was a woman in her late 80s who had thick, short, salt and pepper hair and striking blue eyes. A widow of many years, Eva’s only daughter and her extended family had worked collectively to maintain Eva in the community. They were successful for many years, despite Eva’s advanced state of dementia; she had only come to live at Cedar Grove one year before I began my study. Ultimately, it was her declining mobility that precipitated her move into the facility. Eva required a ceiling lift to get in and out of bed and another type of lift to use the toilet or to bathe and community support was no longer adequate.

When I knew her, Eva’s verbal abilities were limited; however, her non-verbal communications were strong and she affectively expressed her fondness for staff—which they reciprocated. Eva exuded warmth and she would light up when people addressed her by name. Eva also appeared to share in the excitement of group activities and seemed to particularly enjoy the pub events and parties that were held in the common areas. Aside from these times, Eva also appeared to enjoy mealtimes when she had one-to-one attention from a carer. Eva also benefitted from the limited, but continued involvement of her family and friends, who visited when possible and who attended her yearly care conference.
I came to know Eva initially through helping her eat her lunch. Because she had no teeth, Eva required one-to-one assistance to eat. So, under the guidance of a nurse, during early fieldwork sessions I assisted Eva with her noon meal, and in this way came to know something of her and her life at Cedar Grove. One day, I sat with Eva at a single table located against a part of the wall that divided the large windows. The menu included the following: one cup of creamy tomato soup, a small croissant with tuna salad, a few pieces of mixed greens, vanilla pudding with a dollop of cream, apple juice, and coffee. She managed the soup fine, but the nurse said that I had to scrape out the tuna and offer her small bites to help her manage the croissant. Eva ate as if she was hungry and enjoyed the food. Her tongue moved rapidly in and out, and way out when she wanted more food. Her eyes invited more when she was ready. Every once in a while she grinned. I also talked to her as she ate. Once when I asked her how it was, a few seconds later she replied “fine.” Her response reinforced what I had suspected: that in fact she had been following along with what might have seemed like a one-sided conversation. She ate everything but the salad.

While conducting DCM sessions on Holly Street, I found out that Eva spent much of the time she was mapped in a state of borderline behaviour, meaning that she showed no signs of negative mood, and was passively engaged, showing casual interest in her surroundings for the majority of the time I observed her. However, Eva’s mood and engagement rose considerably when a particular staff member interacted with her by making eye contact, touching her, and using her name during an interaction. Also, Eva’s mood and engagement score was elevated when she observed activity around her. In sum,
Eva responded very well to an active social space, to touch, eye contact, and personalized communications in general.

Eva’s health remained stable during fieldwork. She continued to communicate through physical contact and to respond well from the affection and touch of care staff on the SCU.

**Juniper Way: Hannah, Ruth, and Maria**

Within the campus of care that comprises Cedar Grove, Juniper Way is what might be described as a “usual floor.” In LTRC, this means that people, largely though not exclusively, are older and have a range of complex care needs. What distinguishes this floor from Holly Street is largely the fact that it is not a secure floor and so people who live there are technically free to come and go independently. Also, these residents are less likely to have advanced dementia. In part, as an outcome of the population that it serves, the people who live on Juniper Way also have a different relationship to the wider Cedar Grove community. In general, they dine and participate in leisure programs one floor down. Many of the residents on Juniper Way rely on wheelchairs to get around which means that most residents here use the elevator many times throughout the day. The following are vignettes of three residents of this floor: Hannah, Ruth and Maria.

**Hannah.** Hannah was an outgoing, well-groomed, contented woman whose resilient nature enabled her to live well in residential care. When I first met her, she told me about her life circumstances and how she came to live at Cedar Grove. Her story of moving into the facility reflects conditions that might now be considered to represent “the old days” in
Canadian LTRC. That is, more than 10 years prior, Hannah had a few health and social concerns, and she decided on her own to make the move to congregate living. Her decision to live at Cedar Grove was predicated on her failing eyesight related to macular degeneration, osteoporosis, and her concern over her increasing social isolation.

In her early 90’s when I met her, Hannah was an engaging woman who was a politically astute, socially active person who had significant trouble with her vision and difficulty walking. These challenges meant that her care needs (assistance with medications, housekeeping, and physiotherapy) had increased slightly in her twelfth year of residence at Cedar Grove. Until just prior to my meeting her, Hannah had been an active member of the Resident Council, and she continued to participate in the large group activities (for example, seasonal events and pubs) offered in the main lounge.

Hannah’s husband had died many years ago and she had one living daughter who resided within an hour’s drive of Cedar Grove and was involved in her care. Her daughter would visit twice a month, often bringing a few of her grandchildren along. During these visits, the family usually went out for a meal. Hannah described her daughter as “devoted” and her grandkids as “busy teenagers” with active social lives of their own.

Hannah’s warm and personable character made her popular with the care staff. In turn, she spoke fondly of them, noting her respect for the hard work they perform. She also enjoyed many friendships with other residents, many of whom did not live on her floor which meant she travelled frequently to other parts of the facility to connect with them, specifically, to the independent and assisted living sections. As her mobility declined however, her ability to leave the floor to interact with her friends was increasingly difficult. Unfortunately, she wasn’t able to replace these friendships on her
own floor. Hannah perceived a lack of connection with these residents and lamented the inability to connect with other residents on Juniper Way, stating that at one time people had been “friendly” and “involved in a lot of activities,” but in her opinion this had changed in recent years and the floor wasn’t conducive to forming new friendships.

In the following exchange, and in many of our conversations, Hannah referred to a change in the health and functional abilities of the resident population:

Hannah: And there’s so many wheelchairs down at this far end and the people, they’re only about three or four people that I really know. They’re all newcomers.

EK: Okay. You’ve been here a while, living here a while?

A: Twelve years.

EK: Okay. So you’ve seen that change over time?

Hannah: Yeah. There’s been quite a change.

Despite the hardships, Hannah continued to maintain a positive attitude. This was well illustrated in her response to a fall that left her reliant on a wheelchair, and hence other people, to get around. Her decreased mobility frustrated Hannah greatly, but she continued to express hope noting that her doctor had adjusted the medication that may have contributed to dizziness that caused the fall and she was undergoing physiotherapy, so she was optimistic that she would regain her strength and balance and would once again be able to use her walker to come and go as she pleased. If one wanted to know how to thrive in residential care, Hannah could teach you. In particular, she was adroit at taking from her surroundings what she required to meet her fluctuating medical needs, while continuing to maintain the friendships she had that gave her life meaning.
Ruth. Ruth had lived next door to Hannah on Juniper Way for several years. Despite their proximity, the two women knew each other only through cordial greetings and brief chats in the corridors. Unlike Hannah who was born in the province, Ruth came to Canada from Denmark after World War II. She married a Canadian and had four daughters, all of whom now live a short distance from Cedar Grove. Unlike Hannah, Ruth moved to Cedar Grove against her will, preferring instead to manage her life and the challenges of Parkinson disease at home. Eventually, her need for support exceeded her ability to manage, and at her children’s insistence, she moved. This was three years prior to my meeting her.

Ruth considered her autonomy to be an important value in her life. This value is perhaps what she felt was most at risk from her status as a resident. On this topic, Ruth stated: “See and another thing is I can’t go on the bus by myself anymore. You know things like that. And that hurts.” At Cedar Grove, Ruth was usually on the periphery of activity and would often spend the day either in her room alone watching television, or weather permitting, she would use her walker to set out into the surrounding neighbourhood. Once an excellent cook for her large family, she described finding the food at the facility bland and the menu repetitive. She also complained of boredom. Like Hannah, Ruth considered most of the people around her to be “sick,” “sicker than” her. Perhaps because of this, Ruth felt that she had few real friends at Cedar Grove.

Despite her mobility challenges, Ruth coped with her life circumstances by walking. Although in early conversations with Ruth I had attributed her walking to her commitment to keeping active, in an interview she clarified the principal purpose of walking in her life:
Well everything is missing. You know, I don’t feel ever [like I am ] coming home, to my home. I come in, you know, I go to washroom, and then I put my coat back on, and then I go again. I’m always on the go.

Being “on the go” is how she filled her days and coped with her life in residential care. Ruth talked about “home” as though it were another place and another time. A key part of this perception for Ruth was related to a time and place when she had more “freedom.”

In spite of the degenerative nature of her condition, Ruth seemed to be enjoying a plateau health-wise and was still walking daily when I completed fieldwork.

**Maria.** Maria was an 89 year-old petite woman who had been a resident of Juniper Way for just over one year when I met her. She wore an old pair of cat’s eye glasses, trendy once again, with a heavy prescription. Often, she was dressed in fleece jackets that zipped up the front and had various patterns embroidered on them. She was tiny and appeared frail.

Born in a small community on the West Coast, Maria moved to the big city to marry a man she was introduced to at church. She lost her beloved husband when she was in her 70s. Maria had two sons; sadly the eldest died when he was a young adult, but she still enjoyed a close relationship with her youngest remaining child, even though maintaining regular contact with him was a challenge because he travelled a lot with his work. Prior to moving to Cedar Grove she had lived alone in the large, two-storey family home until a stroke left her physically unable to cope. Maria loved the garden and the backyard where her children played when they were young and was reluctant to leave her home.
The move to Cedar Grove was emotionally very hard on Maria. She did not want to move to a residential setting. She had a history of depression and the move left her feeling overwhelmed and for many months she was unable to sleep or eat properly. Maria lived with a variety of chronic ailments and despite her medications, was often in pain. Because of this, she required a wheelchair to travel any distance and when she was in her room she was often in bed. Self-conscious about her situation, Maria frequently denigrated herself, stating that she was “lazy” and that she “should make more of an effort.” When Maria told me, “I like sleeping the most, because then I just disappear,” the depth of her hopelessness was wrenching to hear.

However, there were several times when I was able to spend time chatting with Maria on a one to one basis when her mood brightened considerably and her dry wit surfaced. I discovered that Maria enjoyed talking about history and current events and that she described herself as having been an avid reader, limited now by her vision and decreased attention span. What she still liked to do was listen to local radio and watch the evening news on the television in her room. Maria also liked to attend the weekly social events held in the main lounge. However, she was unable to stay downstairs for long periods of time because of her complex pain.

One of the hardest aspects of her current living situation identified by Maria was the experience of waiting. The amount of time waiting for staff to address her various needs or respond to her challenged Maria’s sense of well-being. Maria shared her feelings on this aspect of her daily life in the following exchange:

EK: Is there anything that you would like to tell me that I haven’t asked you Maria?
Maria: Anything that’s, well there’s one thing [voice breaks] wait, wait, wait, wait.

EK: Wait?

Maria: Everything you wait for it. You just sit in the hallway, and maybe half an hour, an hour goes by.

EK: Before your meal? Is that what you mean?

Maria: For everything that you do, to go down to the elevator, anything, you have to wait for it. And I find that very, and some of the others do too.

EK: Thanks for telling me that. That’s really helpful to know.

Maria: That’s really the only thing that I find really upsets me [voice full of emotion]…it’s a horrible thing. Wait. When I hear that “wait I’ll be right there.” God. And it’s an hour later that they’ll be here. And that’s not their fault. [They] can’t do anything about it.

Her distress appeared to be located in issues of dependency while also pointing to organizational challenges around staffing levels. Although frustrated, Maria did not assign blame. Many months later we had a second interview. During the time in between the two discussions I had chatted with Maria in the halls and in the dining room and had noticed that she always had a book or magazine on her lap. I asked her about it:

EK: And I remember you telling me about this really key thing, that you don’t like the fact that you have to wait. Is that still the case for you?

Maria: I’m more; I’m more philosophical about it I think [voice breaks].

EK: You’re more philosophical about it. How so?

Maria: I’m more accepting. Understanding, of why it has to be that way…
EK: So when you consider, “I’m going to have to wait for the elevator or wait for my meal, I’m going to bring something to do.” Is that what you’re doing?

Maria: Yeah.

Maria had then adopted a coping mechanism to deal with aspects of her care and her daily life over which she felt little control. Her pain and immobility negatively impacted her independence. She was frustrated. To deal with these circumstances, Maria began to bring reading material for the times she anticipated a wait, such as in the line-up for the elevator or at mealtimes. Having access to a book/magazine meant that she was engaged in something stimulating that helped her cope with the waiting.

Chapter Summary

These diverse narrative accounts help depict daily life and the process of culture change underway at Cedar Grove. The women represented in the above vignettes faced different challenges and as we have seen, their overall well-being was impacted by diverse circumstances. The women represented in these vignettes had different personal experiences, life histories, cognitive abilities, mobility issues, medical needs, as well as financial and familial supports. As the vignettes illustrate, residents of the two floors experienced life at Cedar Grove differently. Hannah’s is a story of resilience; she was adept at negotiating life in residential care and had developed important friendships. In contrast, Maria and Ruth felt isolated and their individual needs for social connectedness were not met. Hazel’s ability to find well-being involved a privately paid companion. For Emilia, her ability to retain a strong sense of personal style and independence, despite significant cognitive challenges, is a key part of her experience at Cedar Grove. The
vignettes focusing on Fran and Eva each portray individuals who reached out to others and who were able to use physical gestures to draw others and staff to them. Some of the vignettes describe individuals who had adapted to their lives in residential care in positive ways, while others present those who seemed to be less content and prone to despair.

The struggles and various level of success achieved by these residents provide important insights into the findings developed in the following chapters. The larger institutional concerns and practices developed in the next three chapters directly shaped life for Emilia, Fran, Hazel, Eva, Hannah, Ruth, and Maria and the various other members of the community I got to know at Cedar Grove. These chapters look at how the personal, interpersonal and structural aspects of care intersected to impact life and work in the care culture. In Chapter 6 I explore findings on the complex theme of residents, staff, and collective safety in the culture of care. Chapter 7 deals with the significance of relationship in care practice and Chapter 8 presents the analysis of the data on unstructured activity, social engagement, and the ways in which people finding meaning in their daily lives at Cedar Grove.
CHAPTER 6:
SAFETY FIRST: BALANCING RISK, PROTECTION, AND THE NEEDS OF THE PERSON

In this investigation I sought to understand how a LTRC facility that advanced the “person” in care influenced the daily lives of members of the Cedar Grove community. Through this process, a key theme that emerged regarded the central role that safety played at both practice and policy levels and how influential attention to safety was in shaping people’s day-to-day lives. Issues of safety are core concerns that involve all members of the LTRC community. Data generation revealed a fundamental requirement at Cedar Grove to keep residents and staff physically safe. Operating under the auspices of Residential Care Regulation in the province of British Columbia (B.C. Reg. 96/2009), Accreditation Canada, and the numerous unions that represent workers, Cedar Grove might well be expected to place high values on the provision of a safe living and working environment. Indeed, safety was a major concern in many aspects of the daily management of the facility.

This chapter presents findings in relation to the multifaceted phenomenon of safety at Cedar Grove. The chapter begins with findings that pertain to resident safety, examining data on the various policy and practices employed at Cedar Grove to ensure a safe living environment. As well, it examines the challenges the organization faced supporting resident safety. I then explore data that relates to Cedar Grove staff and their physical safety at work. To contextual this data, I begin this section with a field note excerpt that describes a shadowing session of a bathing care encounter between an RCA
and a resident of Juniper Way. This is followed by findings on the care philosophy, resident immobility, dementia, and workload as key challenges to ensuring staff safety. The final section of this chapter is devoted to collective safety at Cedar Grove and explores data pertaining to outbreaks, quarantine and infection control in the residential care context.

**Resident Safety: Exploring Policy and Practice at Cedar Grove**

*Introduction*

During fieldwork I observed that resident safety at Cedar Grove was a care priority. This realization began with my orientation to the facility, which included having to memorize door codes to the front door and stairway so that I could gain access to secure care floors. These secured access points were designed to ensure that residents on these floors did not get out on their own. In addition to these codes, like staff, I needed a key to allow me to open the door to the stairways or to use the elevator to gain access to the secure floor. My ability to move through the different care floors and areas was in direct contrast with many residents’ relatively limited access within the facility, in light of the institution’s obligation to provide a safe (secure) environment.

In addition to codes and keys, many of the sounds of daily life at Cedar Grove reflected a culture of care in which concern for safety and protection prevailed. Life in the facility was punctuated with different alarms, call bells, and beeping keypads, each signaling a means of protection or potential hazard. Primarily, these sounds were directly related to warnings for residents and their safety.
**Beyond Eden: The Impact of Care Philosophy**

In the late 1990s, Cedar Grove adopted the Eden Alternative model of care (Thomas, 1996) and began a process of culture change based on this person-centred philosophy. Briefly, this model aims to address problems associated with institutional life and the medical model in LTRC (i.e., boredom, isolation, and loneliness) through the creation of a human habitat where children, animals and plants are a part of the daily lives of residents, their families and staff (Eden Alternative, 2006). Early in my fieldwork, this culture change entered a new phase when Cedar Grove officially withdrew their affiliation with Eden. This withdrawal coincided with a new phase of leadership at Cedar Grove. Under new leadership, the organization endeavoured to supplement many of the priorities of Eden with implementation of standards of care as outlined by Accreditation Canada (ACC). This transition was explained to me by an administrator who recognized the diversity of influences on the Cedar Grove philosophy of care and its relationship to the organizational culture:

> Eden is embedded into everything we do, just as is Gentlecare, just as is culture change, just as are any of those philosophies, you name it. We’re eclectic. So the idea is you use what you need for a specific situation.

Ironically, administrators considered the departure from the official designation with Eden as liberating. Specifically, the departure allowed the organization to implement more person-centred care because it gave them the freedom to respond to the distinctive needs of their own context rather than having to adhere to potentially less relevant policies. This same administrator said, “And in many ways it’s [withdrawing from Eden] actually freed us up to be more creative, you know. And more flexible around how we
provide care, the atmospheres we create.” Rather than striving to meet the requirements of a specific model of care in order to maintain affiliation status, Cedar Grove was able to adopt practices and policies that might allow them to be more responsive to the particular needs and the type of culture they wanted to develop. Notably, this decision also entailed financial benefits because Eden membership was expensive.

One of the key missions of the ACC is to promote a “culture of safety” in health care settings. This clear ‘safety’ focus marks an important change in philosophy away from the humanistic goals of Eden’s person-centred care approach to something that, while ostensibly concerned with individual care, tends to support more bureaucratic initiatives—arguably a shift from the person to the institution/organization. The ACC lists “patient safety” as a “high priority area” within their Required Organizational Practices, which they define as “evidence-based practices that mitigate risk and contribute to improving the quality and safety of health services” (http://www.accreditation.ca/accrediation-programs/qmentum/).

Organizational policy documents revealed various organizational policies upon which a prioritization of safety in the culture was rooted and that guided care practice. For example, Cedar Grove’s most recent strategic plan (2011-2013) listed “Safety of Residents” as its primary objective of care. Similarly, achieving “accreditation” was considered a key component in “strengthening quality improvement and enabling patient safety initiatives” (Accreditation Canada, 2010). In 2010, ACC prioritized the connection in health organizations between quality of “worklife and patient safety.” The motivation for certain changes in practice was then rooted in the goal of ensuring resident safety.

This emphasis filtered down to the practice level in myriad ways. For example, whereas
at one time staff could bring groups of residents from the SCU off the floor to join the
wider community in activities offered in the main lounge, safety breaches had occurred
that caused the organization to re-evaluate policy. In light of the needs of current
residents, a policy was implemented that stipulated that one staff person had to
accompany one SCU resident when they left the secure floor. According to one
administrator, implementation of the policy of one-to-one described above was an
attempt to respond to dementia and the desire to meet the unique needs of a growing
segment of their resident population in terms of safety. This issue is described in the
following passage:

And very often people will be completely dysfunctional out there. They’ll come
here [to the SCU] and they’ll do very well. We forget that it’s because we’re
providing a secure environment, where it’s familiar and there isn’t this big world
they have to cope with. So we need to question, who’s that for? Is it really for
[names resident] or is it for somebody else? And we need to take a really close
look at what they are like when they come back up. Are they flying off the walls
overly agitated, unable to sit down and eat, really anxious… at the time they were
having a great time dancing and everything, but was it too much for them? And
how are they when they come back? And there’s the whole other issue of the bus
rides.

As this administrator explained, the change in practice was implemented not to penalize
people, but rather, to offer appropriate (good) dementia care that was designed to meet
the needs of residents with dementia in relation to safety, socialization, and activity.
Similarly, another administrator described this policy as a measured response to the needs of the residents with dementia, locating this practice in the precedence of safety in the care culture. She stated:

So absolutely they must come down [to the main lounge] one-to-one, and that’s safe. That’s safe. So, that’s where you have to kind of balance it out. So that’s why I think we’ve moved beyond Eden.

The model of care, which once informed Cedar Grove had shifted and changed. As they attempted to “move beyond” Eden, they increasingly promoted a “culture of safety.”

RCA Minnie saw resident safety as a primary responsibility of her position. She said:

Most of the time you do what you can do. I mean if somebody’s fallen of course you’re going to have to look after that person before you look after the person who’s crying. I mean…

The changes described here in organizational culture and practice created tensions in the culture. Members of the care culture interpreted these organizational policies differently. What some members of the community (mainly direct carers) evaluated as paternalistic and isolating for residents, others (mainly administrators) considered to be grounded in best practices, which were defined in relation to resident safety. This crux of these differences rested in understandings of approaches to dementia care that seemed to be difficult to reconcile. Whereas some people at Cedar Grove reacted to what they perceived as a restriction of residents’ individual rights and autonomy, other people understood this as the provision of a calm, dementia-appropriate environment that supported rather than curtailed rights.
The Structure of Safety: Stigma, Dementia, and Levels of Care

The physical and structural divisions that help Cedar Grove to maintain a safe living and working environment influenced how residents were perceived by care staff, family members and others. Through the process of data analysis, I detected the presence of a social stigma, negative views associated with individuals’ level of care. Levels of care at Cedar Grove ranged from independent housing to complex care, with each level involving increasing restrictions on mobility/access. In my fieldwork, I interacted with people from across the different areas of the wider community and through these interactions I encountered a facility-wide perception that the level of concern over safety (and conversely, controlling or curtailing of individual freedoms) was “higher” as one went up in levels of required support or direct care. In my conversations with family members, residents, and some staff, I frequently heard them speak about the living situation of residents in terms of the need for protection and conversely, a reduction in their freedom.

Tenants of the independent living spaces at Cedar Grove occupied the bottom tier of this apparent hierarchy of safety, in the sense that there was the least concern for, and restrictions on, their ability to come and go from the facility. Unlike those who lived on one of the complex care floors, these tenants were deemed by others to be relatively “safe” and correspondingly, they were allowed to enjoy more individual freedoms. Those who required assisted living support occupied the next tier up the safety ladder. This meant that these people were more or less free to come and go from the facility as they wished and independently go about their day. Because they were not seen to be as vulnerable or at undue risk for physical harm, people on assisted living floors were
granted a certain level of social status; they were less stigmatized by risk. The next level up were the residents who were considered for the most part to be low risk, either medically or in terms of “elopement” and were allowed to reside on a non-secure floor. Juniper Way is an example of this type of non-secure floor where technically, residents could leave the building when they wanted to. At the top end of the risk/safety spectrum was the special care unit (SCU), Holly Street. Residents of the SCU were seen to be in need of relatively high levels of protection and they were restricted from leaving the floor. The result of this interpretation was a discernible aversion to living on Holly Street that was rooted in its perception in the care culture as being a place of confinement. In formal and informal conversations, comments were made depicting the SCU as marked by a facility-wide stigmatization. The social space of the care facility reflected a hierarchy of safety, risk, autonomy and freedom.

Living in SCU was widely considered to signify seclusion, isolation, and pathologization, and its residents were set apart in the minds of the wider community. Those living in the SCU were most directly connected to problems associated with dementia; their living situation and the risk it was meant to mitigate was a marker of their social position. In the words of a resident of Juniper Way, a move to Holly Street meant you would be “locked up.” Therefore, this space was equated with increased confinement and loss of freedom.

Data also suggested that a key part of the stigma surrounding the SCU related to its association with dementia and end-of-life. People who lived on Holly Street were different that those on other floors in that they were evaluated as a danger to themselves (and perhaps others) and therefore needed protection (meaning

172
surveillance/confine...tion). A family member of a new resident of the SCU described her feelings when the need to transfer her aunt to Holly Street was presented to her: “I hated her to go [to the SCU] because it’s ‘lock-up,’ so to speak.” Another family member summed up her feelings on her relative’s move to the SCU, “Well, it’s palliative care, really,” inferring an association between the SCU, advanced illness, and death. A direct carer offered a stronger reaction to the restrictions faced by residents of Holly Street. In his opinion, “All the main things are downstairs you know. So actually, you’re just reinforcing the confinement. I mean I see it as…well prisoner’s get more rights.” This comment calls to mind the deeply ingrained socio-cultural association of “the nursing home” and its occupants with the prisoner and incarceration (Davies, 2003; Kane, 2003; Goffman, 1961/1991). The question of autonomy, rights, and participation in the wider life of the facility, key aspects of personhood, thus came to be framed spatially and might be said to be directly impacted by Cedar Grove safety (risk management) imperatives.

But given the multi-dimensional nature of LTRC—consider McLean’s (2007b) description of the “nursing home” as “an institution, workplace, a regulated industry, and most often a business” (p. 62)—the situation is complex. Countering the belief that a move to the SCU was tantamount to a complete loss of autonomy and personhood, Barb, a daughter of a resident shared her experience with her mother Rachel’s move “up” in care. Evidently Rachel greatly feared the prospect of increased care within the facility. Barb stated: “And she [her mother] said, ‘no,’ she said, ‘if you put me downstairs [to the SCU], that will, I’ll just die. That will be the end of me.’” Barb further commented that in her experiences in the culture of care, this attitude was prevalent:
It [the association between increased care level, limited freedoms, and mortality] is very common. And if you talk to any of those other women that live down there who have coffee, it’s very common. It’s like you are going to be put to death basically going down there. That’s the mindset.

In spite of this perception, once the move was made, Rachel thrived. As a result, Barb felt that her mother’s need for increased support and care and subsequent move might have been instrumental in reducing stigma in her social circle. It seems that when her mother moved to Juniper Way from assisted living (a transition made possible by the Campus of Care), she maintained friendships from her previous living situation in the facility and developed a wider circle of friends. Following visits, these community-dwelling friends shared with Barb their perceptions that Rachel’s new living arrangement “wasn’t that bad after all” or words to the effect.

Findings on the structure of safety point to the creation of social stigma that was experienced by members of the culture in varying degrees. Of the range of care levels available at Cedar Grove, the SCU was perceived as the pinnacle of support and correspondingly, of restriction. Because of their increased dependency and reduced capacities, the residents of the SCU were viewed as those who were unable to exercise autonomy and self-determination. Many people expressed fear of a time when they might require more help and care, which they equated to living in the SCU. The problem of safety and the need to manage various types of risks presented itself as a central issue and challenge in Cedar Grove’s attempt to create and deliver care that was respectful of individuals or what I might call person-centred care.
“Challenging Behaviours”

Dementia affects the cognition, mood and behaviour of the person, and for many people with dementia is associated with the desire or need to walk. This propensity for individuals to walk, seemingly without purpose, has been defined in the gerontological literature as “wandering” and classified as one of the myriad behavioural disturbances that accompany a dementia (Beattie, Song, LaGore, 2005; McLean, 2007b).

Data showed that at Cedar Grove “wandering” raised complex issues for care staff and for residents. A general fear of elopement/wandering were often motivating factors behind many residents’ move to the secure floor. Specifically, admissions to the SCU were often precipitated by an “elopement” incident that was perceived as a safety/risk-related incident—either at home, in the community, or from another unsecure care floor of the facility. Elopement/wandering incidents seemed to be the “last straw” in a series of events whereby the person was deemed to be at risk by family or care staff.

Three resident’s stories – Stan, Emilia, and Ruth—illustrate how daily lives were shaped by concerns for wandering that would challenge their physical safety at Cedar Grove.

Stan. Stan had lived on the SCU for the three years and had a long history of attempting to, and successfully, leaving Cedar Grove. His unstable gait put him at moderate risk to fall and he would not make use of an assistive device. Stan was a heavy smoker and it was important for him to routinely leave the unit for a habitual cigarette. However, his frequent desire to go downstairs to smoke was impossible for the staff to accommodate
but it was considered unsafe for him to leave the unit unaccompanied by staff or a relative.

One cold day Stan decided to leave the building. He was not properly dressed and had no money. Aside from his unreliable mobility, his dementia—in the opinion of administration—left Stan vulnerable to traffic and strangers. When it was discovered that he had left the Cedar Grove premises, a “Code Yellow” was called. A universal emergency code, yellow signifies a missing patient, or in this case, a missing resident. After a couple of hours of searching by staff and the police, Stan returned to Cedar Grove of his own volition. Rather than focusing on the fact that Stan had indeed travelled safely into the community and back again, this breach of security highlighted the need for staff to increase vigilance around the elevator, and encouraged them to use the stairs themselves because these were out of the way and less likely to encourage residents to attempt to follow.

Emilia. Emilia was a resident of Juniper Way and as she had become increasingly disoriented and physically unwell, she had been fitted with a security bracelet. Security bracelets were used to alert staff that a resident deemed at risk was leaving the building. A panel in the foyer helped staff to identify which resident had made the attempt. One day, Emilia removed her security bracelet and then went down the elevator and out the front door undetected. This caused significant concern, and as demonstrated in the following excerpt from an interview with an administrator, helped place Emilia in the SCU:
But it’s cold. She’s totally disoriented. She’ll be mugged for sure. And given the choices, I can’t let her be hit by a car, be mugged, or spend all night outside. I can’t in good conscience, because to me that takes precedence. It’s different in every situation and if I knew she would just go to sit there and then come back, maybe, but no, she’s off as fast as she can be…so eventually she went to our secure unit.

It is important to note that Cedar Grove administrators alone did not dictate Emilia’s move to Holly Street. Rather, the decision was made in consultation with her family. The administrator quoted above went on to say how difficult the decision was:

But we struggled because we can see how important it is for her to want to walk outside on her own. The family in this one, I don’t think the family struggled as much as we did. [The family member said] “of course put her in the secure unit.”

Family entrusted Emilia’s safety to the care of Cedar Grove and it was the family’s expectation that Emilia’s physical safety would be looked after, first and foremost. Emilia’s propensity to leave the building challenged staff resources. Weighing Emilia’s safety and the risk involved in her current living situation against the loss of her freedom, it was decided soon after this incident that Emilia move to the secure floor.

Ruth. Like Emilia, family featured prominently in considerations of resident Ruth’s physical safety, and ultimately they made the decision to restrict her ability to come and go from Cedar Grove as she desired. Ruth also lived on Juniper Way, where residents were encouraged to “sign out” if they planned to leave the building. In actuality, with an increasing number of the residents of this floor reliant on a wheelchair, few of the
residents were ambulatory and therefore few were able to independently leave the floor. Ruth was an exception. She was both ambulatory and often interested in leaving the floor.

Conversations with Ruth about her daily life and activities revealed that “achieving safe care,” (Accreditation Canada, 2012-2014) meant monitoring and restricting her movement, which had an impact on her personhood and capacity to consider Cedar Grove home. For Ruth, her ability to go outside unaccompanied was inextricably linked with her self-definition and conception of freedom. Ruth told me that part of the reason she did not consider Cedar Grove to be “home” was because her “freedom is gone.” This opinion challenged her perception of herself as an autonomous agent:

EK: So you’re quite independent?
Ruth: Yeah, very independent.
EK: Is that important to you?
Ruth: Yes it is. See and another thing is I can’t go on the bus by myself anymore. You know things like that. And that hurts. I used to have a bus pass and I go everywhere with the bus pass. And I miss that.
EK: What happened to it?
Ruth: Well my family thought that I should stop.

Regardless of so-called rational concern by administrators or family members, Ruth felt punished and infantilized. Her sense of self was undermined. Ruth valued her autonomy and equated her bus pass to “freedom;” without it, she felt restricted and that her independence had been taken away from her. Interestingly, Cedar Grove deemed Ruth “safe” to leave the facility for unsupervised outings in the neighbourhood, but her family

178
curtailed her ability to go much further afield via public transit.

The decision to curtail the freedom of residents Stan, Emilia and Ruth was not taken lightly at the management level. Each presented dilemmas to the organization; their walking and exiting behaviours were constructed as problematic in the discourses that shaped practice. Consistent with descriptions by Dupuis, Wiersma and Loiselle (2012), their actions were seen through a “lens of pathology” (p. 165) and were assigned the labels of “wandering” and “elopement.” For these residents, the inability to self-determine his or her access to the wider community negatively impacted their well-being. This aspect of LTRC challenged Cedar Grove’s aspirations for more balanced person-centered care. Vigilance around these problematized behaviours was an organizational priority, however, there was also evidence of Cedar Grove struggling to negotiate the individualistic needs and desires of residents. This was after all, in keeping with their mandate to provide vulnerable people a safe living environment.

**Preventing Falls: “Keep Mum Safe!”**

The risks associated with individuals leaving the building were not the only consideration made with respect to residents’ physical safety at Cedar Grove. In addition, a vital component in the quest to keep residents safe was the management of potential physical harm incurred through falls within the facility. Given the well-documented deleterious effects of a fall on frail older people, which is associated with high levels of morbidity and even mortality, fall prevention measures are logical and necessary in this context. Recent statistics on falls in residential care indicate that 30 to 50% of residents experience a fall each year and 40% fall twice or more in a year (BC Injury Research and
Prevention Unit, retrieved September 5, 2012). Indeed, falls are the most commonly reported adverse event in LTRC (Grunier & Mor, 2008).

In this study, findings suggested that weighing resident freedom and safety in the context of fall prevention was not straightforward. Experiences of daily life were infused with concerns over how to minimize the potential to fall and decisions around how to balance risk and mobility was addressed through the organization’s care planning processes.

The experience of SCU resident Violet and her family around fall prevention illustrates the complexities of fall prevention in residential care. When Violet’s son said, “keep Mum safe!” he summed up an attitude that was prevalent in the culture, one that often informed care decisions. Following a series of strokes and a significant decrease in her mobility and cognitive function, Holly Street resident Violet became increasingly unstable even with her walker. She was deemed to be at high risk for falling. Hip protectors were ordered, which Violet hated and would not wear. One day, she fell and incurred a wide array of injuries, though no fractures.

Her family was involved in the decision-making around Violet’s safety following the incident. Guided by least restraint regulations, the care team met with the family. Weighing the pros and cons of Violet’s situation, the family decided that a restraint was the best way to “keep Mum safe.” For them, fall prevention was paramount. As per standard of practice in British Columbia, an agreement in writing was attained (Director

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5 This Standard of Practice is made under the authority of section 4(1)(e) of the Community Care and Assisted Living Act (the “CCALA”), which permits the Director of Licensing to “...specify policies and standards of practice for all community care facilities or a class of community care facilities....”
Section 74 of the Residential Care Regulation, which is made under the CCALA, provides as follows:
1) Subject to subsection (2), a licensee may restrain a person in care (a) in an emergency, or (b) if there is agreement to the use of a restraint given in writing by both
(i) the person in care, the parent or representative of the person in care or the relative who is closest to and actively involved in the life of the person in care, and
of Licensing Standard of Practice, October 1, 2009) and signed by the family and a
medical practitioner, Violet’s doctor. It ordered that Violet be restrained in a wheelchair.
Cedar Grove then implemented the doctor’s orders and Violet’s wheelchair was fitted
with a lap belt in order to prevent future falls by confining her in the chair.

Violet’s situation was not unique at Cedar Grove. For each resident,
administrators, care staff and family members (if involved) conferred over adjustments to
care plans, particularly in relation to changing mobility and fall prevention. Because use
of a lap belt is not without its own risk to resident safety and well-being, the decision to
employ one is not clear-cut. An administrator noted that although family generally
supports their use, lap belts have the potential to create stress and potential risks for the
user/resident. She was concerned that: “you’ll have more injuries trying to get out of that
chair if they’re strapped in and getting anxious and upset.” Weighing her experiences
with the risks and benefits of lap belts, this administrator and other staff I
spoke with, preferred to risk a free fall rather than use this form of restraint. Unlike most families,
they had direct experience with the potential danger lap belts could pose and were
reluctant to use them whenever possible.

**Surveillance and Space**

The physical structure of the facility shaped social life at Cedar Grove and
correspondingly, influenced considerations of resident safety. On Holly Street, as noted
earlier, the dining room was a multipurpose room that also functioned as the main social
area on the floor where leisure and unstructured activities usually took place. During the

(ii) the medical practitioner or nurse practitioner responsible for the health of the person in care.
2) A licensee must ensure that a person in care is not restrained (a) for the purpose of punishment or discipline, or (b) for the

day, the majority of residents spent most of their time in this space. In the summer months, the doors from the dining room opened onto the terrace (See Appendix A) and permitted residents to safely enjoy the gardens and the outdoors.

Consistent with the description of a characteristic institution detailed by Goffman (1961/1991) and Foucault (1967/1984, 1980), the social space of Cedar Grove functioned through systems of monitoring and surveillance. This was especially true of the SCU. One outcome of encouraging residents of Holly Street to congregate in the dining area was that it meant fewer staff were required to attend to the resident population. The following scene from my field notes provides an accurate description of daily practice in the SCU common area:

10 a.m. – Dining Room - Holly Street:

20 or so residents scattered throughout space.

Robert sitting in his wheelchair, facing wall moving his hands around the table in a wiping motion.

Margery in her robe, looking more chipper today.

A few people finishing breakfast.

Trudy eating eggs, sausage, toast and jam.

Classical music quietly playing.

A few residents resting in their beds and not up for breakfast yet.

Five RCAs on shift this morning, two in and out of dining area.

Observations of this space revealed how the practice of encouraging residents toward common areas for meals and other social interactions enabled staff to monitor residents and to oversee their safety. For example, direct carers were able to respond
quickly to a potential safety risk, such as a resident getting out of his or her wheelchair
unassisted. The quick action needed might not be possible if residents were dispersed and
alone in their individual rooms. Visibility of residents also helped staff to intervene in
resident-resident conflict. If two or more residents began to argue, an RCA could respond
quickly to the situation, thus, preventing the likelihood of the situation escalating. On
Holly Street, residents who did not spend most of the day in the common area were
usually receiving end-of-life care and were confined to their room. There were several
others who stayed in their room to watch TV, nap, or read, but these were in the minority.

Mitigating Social Isolation: The Role of Private Companionship

Earlier in this chapter I described a change in policy that created tensions at Cedar
Grove. Whereas at one time residents from the SCU had been able to leave the secure
unit if in the company of a staff, irrespective of whether there was more than one
resident. This allowed them to join others for activities offered in the main lounge. After
an SCU resident left the building unobserved during one of these events, administration
responded by determining that a one-to-one ratio was now required. Some people were
unhappy with the new policy. Several direct care staff described this shift as punitive.
Opponents of the decision felt that it further segregated Holly Street residents from the
wider community, because of the limited number of staff and their general lack of ability
to offer “one to one” support beyond isolated incidences/occasions. In contrast,
proponents of the decision, largely administrators, cited research in dementia care that
favoured a more structured, less chaotic, activity space for persons with dementia. In this
view, rather than being a disciplinary measure, this policy helped move the organization
forward in terms of optimal dementia care.
Interestingly, one of the outcomes of this decision was the addition of a privately paid companion for some residents. Because of the change in policy and the already substantial demands on SCU staff, family members who wanted relatives to be able to leave the secure floor with regularity and safety, were presented with the option to employ a privately paid companion.

Resident Hazel was an example of a person from the SCU who was assessed as likely to benefit from a companion, given her frequent bouts of anger and frustration and her love of the outdoors. Many times I ran into Hazel with a companion, usually Maria, as they made their way to and from a walk in the neighbourhood. During these times, Hazel’s mood was noticeably elevated; she would smile and make small talk as she passed by. Having a companion also meant that Hazel was enabled to participate in the larger activities like dances and holiday parties offered in the main lounge. Since she had no family, a friend that was involved in her care provided the necessary support/advocacy to facilitate Hazel’s companion service. Hazel possessed social power that many of her peers did not, namely, her access to financial and social supports and these could be drawn upon to positively impact her day-to-day life in the facility.

The presence of paid companions was interesting to observe in the social spaces of the facility. Their involvement positively impacted both the resident they were working with and other residents. For example, during a party on the SCU a companion might interact not only with their assigned resident, but also with others, motivating them to dance or sing. I also observed a similar contribution through companions’ facilitation of resident-to-resident interactions such as informal conversations. Given the shortage of
staff, the contributions of companions during structured and unstructured activities were vital and helped foster a positive social context for all residents.

Evidence of a private companion’s contribution to social inclusion was captured in field notes from morning and afternoon PO sessions. In the first field note, I recorded an exchange I had one morning with Hazel in the common area of the SCU:

EK: How are you?
Hazel: How could I be in here?
EK: You’re not happy?
Hazel: I’m cooped up, how could I be?

Later the same day, I noted another interaction with Hazel. This time she was in the main lounge accompanied by Maria, her companion, and her mood had improved considerably:

On the way out today I saw Hazel, seated in a love seat on the main floor lounge. Sandwiched beside her was Maria (companion). The two were chatting to one another while they ate ice cream. Hazel appeared to be quite animated. I went over to say goodbye and found Hazel to be in fine form. Licking her cone, she called me “Liz” in a teasing way, with a twinkle in her eye (she referred to my nametag). She was so much happier and lighter in mood than she had been in the morning. She told me that when she was a kid at school they called her “Haz-hell.” The difference between the Hazel in this space and the person I encountered this morning in the SCU was striking.

These contrasting experiences suggest the potential contribution a companion might make to a resident’s well-being.
Other residents also employed companions. Resident Olga employed a companion named Tommy. This woman had experienced a series of strokes that left her unable to walk or speak (though she could move the wheelchair using her feet). Although safety was a part of the familial decision to connect Olga with a companion, it was also rooted in her communication challenges and high level of sociability. Her family worried about her isolation and desire for social connections and so employed a companion for the many hours that they could not be with their mother. The relationship between Olga and her companion was extraordinary. Watching the two interact was both inspiring and instructional:

Tommy is warm and affectionate with Olga, as she is with him. The two seem to communicate well, largely without words. They have been together for 11 months. She scoots around in her w/c, amazingly adept at maneuvering it given her paralysis. He cares for her, making sure she eats, gets to the bathroom, etc. Yet, he also steps back and lets Olga do her thing. For instance, he did not thwart her behaviour today when she dragged a garbage can from one side of the room to another. He seems to let her be. He does not interfere with how she interacts with the world. (PO Field note)

Hazel and Olga had the financial resources to afford the additional expense of their private companions. This was not the case for many residents at Cedar Grove\(^6\). As an administrator explained, “about 30% or 40% of our people” pay ”the lowest possible rate” for their residency at Cedar Grove and were unable to pay anything extra. Hazel had a good pension and therefore the means to enable her to purchase another level of support.

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\(^6\) During fieldwork, only 6% of residents at Cedar Grove employed a private companion.
and care, beyond what the LTRC facility could provide. Olga, on the other hand, had a supportive family who were willing and able to help her meet her financial needs. Because of their relatively comfortable economic circumstances, these two women were able to obtain one-to-one support and care they might not otherwise access.

By the end of my fieldwork, I noted that Hazel and Olga had begun employing their companions five days a week for three to four hours per day. The positive impact on these residents’ quality of life, while also contributing to their physical safety, was considerable. With the support of these companions, these women were able to enjoy the wider community in a way that minimized risk. This was the case with the other residents who employed companions that I encountered at Cedar Grove. In addition, staff I talked to about the presence of companions expressed their support for this addition to care, citing the obvious benefits to the resident in terms of socialization. This harmony might also result from the small numbers of companions in use at the time, as well as the clarity of the guidelines around companions’ presence. Namely, companions’ duties were strictly social in nature and did not extend to the medical needs of residents.

**Preventing Conflict**

Another facet of the organization’s concern for residents’ physical safety involved violent conflict among residents. This aspect came up repeatedly during my fieldwork. During site visits, I observed many minor skirmishes between residents. Most of these encounters were verbal and tended to dissipate on their own, or care staff rapidly quelled them. Staff was mindful of the potential for flashpoints to escalate and demonstrated that they were adept at keeping conflicting parties separate or employing other preventative strategies. A direct carer from Holly Street noted that staff were good at “putting out
fires,” meaning they showed remarkable vigilance and responsiveness to the tensions that bubbled up from time to time. My observation of one such event is detailed in the following field note:

When I tried to leave Holly Street this evening Violet followed me down the hall, so I walked back toward the nurses’ station with her, not wanting to close the door on her. She led me into her room and said something about her hat and put it on. Nora then came into the bathroom (uninvited) and pointed at Violet and said something that I didn’t understand, but her tone suggested it wasn’t a complement. Violet’s temper flared; she was immediately angry and yelled, “*why are you pointing at me!*” I was amazed at how this had escalated so quickly and worried that it might go further. I quickly led them both out of the confined space of the room.

On another day on Holly Street, I was part of an altercation between residents:

While out for a walk on the terrace with three residents, Hazel, Estella and Hilda, a conflict occurred. Hilda insulted Hazel and she stormed off. She appeared to be furious. Hilda had said aloud, referring to Hazel, “*why is she with us, she’s driving me crazy, I just can’t stand her.*” Later, she said something to Estella that was similarly offensive, except that Estella did not react and we carried on looking at the various herbs together. On the way back we passed by Hazel who was seated in an outdoor chair, arms crossed, perturbed, and muttering to herself. Hazel has been having a difficult time lately and I am sure this incident was the last thing she needed. Hazel was unable to recover from the moment of conflict. In contrast, although Estella noted the cross words from Hilda, and I believe
understood their intent, perhaps because of her personality she did not take the negative comments to heart and moved on.

Living in close confines with others presents challenges in residential settings, a fact well documented in explorations of institutional living. Cedar Grove was no exception. A significant source of friction that I observed on the SCU reflected the challenges associated with congregate living with respect to privacy and control. For residents the ability to protect their private spaces and personal possessions was important. Conflict often arose between residents when people entered private rooms uninvited. Missing articles of clothing/laundry was an on-going concern and often at the centre of altercations. Ambulatory residents regularly went into other’s rooms creating fights and accusations of theft. Recognizing this as a problem, Cedar Grove employed a system of yellow banners in the quest to deter this behaviour: Yellow banners made of nylon with Velcro strips were affixed to the outside residents’ doorways with the idea that this barrier would visually block unwanted visitors, even if the door remained open (See Appendix A). It seemed to offer a moderate deterrent. However, vitally, it allowed residents a feeling of control over their private space. Given the link between access to privacy and experiences of “home” (Chaudhury, 2008; Hauge, Haggen, 2007; McColgan, 2005), this finding identifies a critical source of residents’ autonomy and well-being in LTRC. A resident demonstrated to me how she used the yellow banner when she left her room, noting: “I put this here to keep people out.”

Ethical Issues: Power, Advocacy, and the Role of the RCA

Issues of resident safety at Cedar Grove also involved making complicated assessments of individual risk. Stan, Emilia and Ruth’s situations (detailed above) that
each entailed risk around wandering, as well as Violet’s risk of falling, demonstrate this. Each case also highlighted how decisions related to resident safety involved an ethical component. When an administrator stated, “in good conscience,” with respect to the assessment of Emilia’s impaired judgment and physical frailty, she underscored the ways in which the need to ensure residents’ physical safety were infused with ethical decision-making around resident care.

During data generation I encountered numerous situations involving resident safety that included an ethical component. For example, in resident Ruth’s case, the decision to move her to the secure unit was multifaceted and came about not solely through adherence to a fixed regulation, but rather was considered in light of her unique circumstances, on a case-by-case basis. Administrators (with input from direct carers) considered Ruth’s safety and placement within the facility, taking into account her daily habits and preferences, as well as the potential risks associated with her daily habits. Ruth loved to walk in the neighbourhood, yet she could not independently find her way back or safely cross the street. In this way, although the language of personhood was not used in the discourses of members of the culture of care, deliberations that considered Ruth in the context of life history and personal preferences informed decisions around her safety. This was not an easy process, as observed in the words of an administrator: “So I think the best thing we do here is we do go through a lot of angst about each individual person.”

Decision-making around resident safety also involved input, when possible, from family members. Family members, understandably, were concerned with the physical safety of their loved one at Cedar Grove. However, in conversations with direct carers, I
learned that tensions often existed between family expectations and professional opinions. Examples of areas where the opinions of family conflicted with the opinions of professional carers were around issues of placement in the facility, the need to wear a wandering bracelet, or the use of physical restraints. This aspect of care will be developed later in this chapter.

During fieldwork, I encountered a rich example of the complexities involved in ethical decision-making in relation to resident safety. An example occurred with Jeanie, a resident of Juniper Way who had, conservatively speaking, more personal possessions than what might be considered acceptable or safe, in her private room. In fact, her room was overflowing with old books, clothes, knick-knacks and other belongings to the extent that care staff found it difficult to enter her room and she herself could hardly move in the space. She told me about her various possessions, many of which she acquired in her travels. Jeanie self-identified as a writer; she had numerous boxes of books stored in her room. It was clear that her sense of self was located in her personal objects and she felt threatened by attempts to remove them. A solution needed to be found. In order to move beyond this stalemate, in a way that recognized the degree to which this resident’s belongings were an expression of self, administrators embarked on a process of negotiation with this resident. Safety officers from the fire department were consulted. After many meetings and negotiations with the resident, a decision, that if not exactly mutually agreed-upon, was at least a gesture in that direction, was made to place limits on new possessions, and in the interests of collective safety, ensure that fire regulation standards were met. In this situation, again, regulations were tempered with recognition
of the unique needs of the individual. Yet, the bottom line was met and safety rules were 
upheld.

Data suggested that not only do administrators struggle with the ethics of keeping 
residents safe, so too do direct carers. Care aide Trudy told me that despite her many 
years on the job she struggled to meet the ethical challenges presented to her on an almost 
daily basis. One source of angst Trudy talked about was located in diminished LTRC 
resources that in her opinion had a detrimental impact on residents:

For example if somebody falls and breaks their hip, we used to have a hip 
protocol put in place, and it used to work and we don’t have those resources 
anymore in terms of, if you get that person walking again, then they aren’t put in 
that category of someone whose quality [of life] has diminished to the point 
where you can make that decision [downgrade degree of intervention]. So we are, 
from the start I think, not doing the best we can…

Here, RCA Trudy identified the need for an increase in allied health support, such as 
physiotherapists, to maximize residents’ mobility and contribute to fall prevention and 
general well-being. Other staff made similar comments.

RCA Trudy also expressed feeling the need to advocate for the residents she 
provided care to, especially in situations where residents had no family or significant 
others to speak on their behalf. Trudy shared several examples from practice that she felt 
posed ethical dilemmas. One example she gave related to a care decision that in Trudy’s 
opinion was made unilaterally by administration, without the input of the resident’s 
family or support network. In this case Trudy was troubled because the resident did not 
have an advocate outside the organization: “And she had no family to fight for her, right.
If they have family to fight for them, that’s different.” This quote portrays a sentiment shared by a number of direct carers who perceived residents without involved family as lacking vital support within the facility.

Staff responded to this type of situation in care in several ways. Some people spoke of the feeling that they became a pseudo-advocate for “their” residents. It seemed that a resident’s perceived need for staff support increased in the absence of the active involvement of a significant other. However, staff also shared the opinion that their ability to advocate for residents was hindered by their relative lack of power in the organization. RCA Trudy summed up the frustration involved in this view when she stated:

And we have very little clout or power because those voices don’t matter. They can’t take a piece of paper and fill out a complaint. And so we complain on their behalf, but…

In another conversation, Trudy elaborated on this outlook:

As a care aide we have no power. And they [residents] have no power. It really ticks me off because you know, families have a lot of power. And that’s evidenced by what happens on the floors. The squeaky wheel, right?

Part of the ethics of caring for residents as described by Trudy entailed speaking for those members of the culture she perceived as lacking influence or in other words, the voiceless. In this discussion, Trudy also shared her opinion that residents with involved family occupied a privileged position at Cedar Grove. According to Trudy and other direct carers I spoke with, the perceived need to advocate for the care needs of some residents contributed to feelings of distress in relation to their perceived lack of power on
the care team. For Trudy and other carers, this distress seemed to be rooted in the perceived marginalized space shared by RCAs and residents where both lack the “clout” necessary to advocate for their respective needs within the culture of care.

Findings point to a shared responsibility for resident safety across care roles at Cedar Grove. The quest to ensure resident safety was complicated and involved ethical decision-making that sought to balance residents’ safety with well-being. For RCAs, these decisions were particularly challenging in that they felt pressure to advocate for seniors, especially for those without family, and yet they experienced feelings of powerlessness within the organization to make a difference in the lives of residents.

Spending time at Cedar Grove, I learned that although the imperatives of resident safety and staff safety were intricately connected, they also possessed unique challenges in the residential care context.

**Cedar Grove Staff: Physical Safety at Work**

Physically demanding job requirements and a variety of different safety risks are characteristic of direct carers’ work life, and as such, concern about workers’ physical well-being and hazards faced emerged as a recurrent theme in the data. During fieldwork, I observed front line workers lift, hoist, and bend, stretch, and twist many, many times in a day while providing care to people who were physically frail and/or immobile. In their daily routines, these carers also walked many kilometres a day—up and down corridors and stairs in the facility. In conversations, RCAs often referenced the various aches and pains they lived with as a result of the physical challenges of their jobs. In addition to the physical challenges, some members of the care team expressed concerns over their exposure to chemicals used to sanitize the facility. One member of the team, a
maintenance worker, spelled out some of the physical requirements of her job: “Cleaning the bathroom, bending all the time…and there’s the chemicals too…it’s a very hard job.” In recognition of the scope and nature of direct carers’ jobs and the particular challenges they face daily, administration, together with the regional health authority, the union, and licensing bodies sought ways to prevent, regulate or lessen safety risks for the workforce at Cedar Grove.

This section begins with a lengthy excerpt from a field note that serves to illustrate the complexity of care practice and staff safety in relation to resident mobility. Following this I will develop the four key areas of care practice in which direct carers’ physical safety was highlighted as an important issue. The first area is associated with resident (im)mobility and the quest to reduce injury to staff through the use of a range of mechanical supports (lifts and slings). The second area relates to policy changes designed to reduce risks associated with providing care to this population. These changes were identified as challenging direct carers’ perception of their role on the care team. The third area that was highly influential in considerations of staff safety was found at the intersections of time constraints and workload. Within this dynamic, data on the interrelationship of care philosophy, job requirements, and care quality will be developed. Finally, I will further explore the data on resident “aggression” or “violence,” another significant facet of staff safety.

_Lifts and Slings: A Bathing Care Encounter_

Through observation sessions, I came to understand this aspect of care as a physically demanding task that (ideally) required staff to do several things simultaneously: 1) Operate equipment properly, 2) Work efficiently, 3) Employ
appropriate communication skills to reassure vulnerable residents and help them feel safe, and 4) Preserve residents’ dignity throughout the care encounter. The following field note passage illustrates the amount of physical labour and exposure to risk that is involved in helping someone who cannot stand or move independently to bathe. In the exchange, it is clear that resident Mary was compliant, if not keen, to bathe, so the complication of her “resistance” to care was not a part of this care encounter (implications of refusal or “resistance” to care on the safety of staff will be discussed below). These notes are based on a shadowing session of a bathing encounter between RCA Anita and Mary, an immobile resident that involved the use of several lifts.\footnote{It should be pointed out that care staff made use of a variety of mechanical supports to prevent injury and to facilitate care. A ceiling lift was used to help with residents who were unable to move independently, or with minimal support, to or from bed, for example. For people who were unable to stand independently, staff used a “sit-to-stand” lift. This lift was portable and allowed one staff member to help a resident, for instance, get out of his or her wheelchair, use a toilet, or get into the bathtub. Observing the use of these supports, the skill needed to properly operate them, all the while interacting with the person in a way that made them feel secure, was considerable.}

RCA Anita was working a bathing shift today and I asked her if I could join her for a while to see what was involved in this aspect of care. Anita has been an employee for just over 10 years. Her first responsibility of the day was to bathe Mary. I had met Mary many times prior to today. She has lived at Cedar Grove for the past year. Mary is a soft-spoken, petite, frail woman who contributes to, though does not initiate conversation and chuckles quietly when something strikes her as funny. She appears to be extremely tired. Anita was willing, so I then approached Mary to see if she would consent. Mary was still in her bed when I first saw her. When I asked her if it was okay if I observe her that morning, because I wanted to learn about this aspect of care at Cedar Grove, she replied, “yes, sure.” So once Mary finished her breakfast (she received her meals on a tray...}
in her room) I observed Anita hoist Mary out of her bed and into a wheelchair and then accompanied the two down the hall to the spa room.

Anita started to take off Mary's nightgown and then stopped. Before proceeding, she went over and turned on the shower (Mary’s preference) to warm up the water. This preference meant that Mary did not have to transfer into the tub. Steam soon filled the windowless room. When it was at a good temperature Anita got Mary undressed and wheeled her and her wheelchair into the shower stall. Anita chatted to Mary throughout. While in the shower, Mary was still wearing the mesh harness used to get her out of bed. I was told that she would use it again to get her back into bed, at which point Anita will switch it for a dry one. Anita started out by spraying a small part of Mary’s body with the hose to ascertain if the water temperature was okay for Mary. Mary nodded her head indicating that the temperature was okay. She was slumped in the chair and didn’t speak while Anita worked. Anita used a facecloth, soaped it up, and proceeded to scrub Mary in an efficient way. The soap was odourless. Anita kept the nozzle on Mary as much as she could so that she wouldn’t get cold. Mary had recently had her hair done in the salon downstairs, so Anita didn’t shampoo it today.

Following a thorough wash, Anita pushed Mary into the middle of the tub room where she wrapped her in towels that had been in a warmer. We went back down the hall with Mary wrapped up in towels.
The job of bathing residents included dressing the person afterward. Below, I discuss what the care encounter involved after the shower⁸:

Anita used the lift to hoist Mary back into bed, changed the sling by repositioning Mary several times, and then dressed her in the clothes Anita had picked out earlier (a white turtleneck and a purple house dress). Mary wasn’t consulted on the decision of clothes she would wear that day. Once dressed, Mary went into the dry hoist to be rested in a medical recliner. Once she was placed, plopped really, into the recliner, Anita wrapped a purple blanket around her. Mary said nothing during the transfer.

Once Mary was dressed, Anita opened the drapes to a dull day and I began to once again interact with Mary. Facing the window, Mary squinted into the daylight. Anita asked Mary if she wanted her TV on, which she did; Anita then put on the set and left. Mary wanted to watch “Quincy;” her DVDs were in the drawer and I put an episode on for her. I thanked her for letting me spend time with her. She responded sleepily. It was almost lunch. Anita had left to return to the spa room to clean up (a task that involved using disinfectants in the steamy bathing room) taking the dirty clothes with her to deposit in the laundry. Mary had nodded off by the time I left her room.

During a shift, Anita will bathe 4 or 5 residents all with various stages of mobility, cognitive status, and willingness to bathe. Of these, maybe two might be considered as “heavy” (as Mary was) because they are more physically demanding on the carer. In addition, she is responsible for laundry produced by

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⁸ Reflexive note - Despite Mary’s consent, I was anxious. I was concerned about her privacy and how I might carry out this observation session in a way that shed light on this daily event in LTRC, while minimizing my impact on the care encounter. As a way to offset the negatives, that included my own discomfort, I stood back, and tried to maintain a physical position on the periphery.
the residents she bathed that day. Anita is given half an hour per resident to complete the above tasks, except that a bath often involves washing and drying a resident’s hair.

When Anita was finishing up today an LPN came in to the spa room and asked her to work an hour longer. Anita agreed.

**Evaluating Risk: Resident Im(mobility)**

One of the main sources of risk to care staff was located in the considerable physical demands that carers faced providing direct resident care. Often, staff had to deal with the physical challenges associated with restricted mobility and immobility of a large (and increasing) portion of the resident population.

Upon moving to the facility, residents are assessed as a “new admission.” Part of this process involved establishing their risk for falling, and the related level of assistance staff need to implement to enable them to help move a person from one location (e.g. the bed) to another (e.g. a wheelchair). A person could be evaluated as: “independent;” a “one person transfer;” a “two person transfer,” or “total body care” meaning they required a mechanical lift. These designations were linked to risk of falling. For example, a person who was immobile and required a ceiling lift and sling was evaluated as a “low risk” to fall while someone who required a one-person lift might be evaluated as higher risk of falling. It is important to consider that just because the resident was assessed as requiring a certain level of support, it did not necessarily follow that the resident wanted or would accept assistance. Mobility and need for assistance was once again discussed following a critical incident (for example a hip fracture or stroke) or in annual care-planning meetings. These levels of support and fluctuations in resident’s requirements
around mobility, such as following a hip fracture or a stroke, were discussed in brief daily care meetings and in more depth, in care plan meetings among the care team (though rarely with RCAs), and when possible, residents and family members.

In care conferences I learned that in consideration of the potential physical harm to staff (and residents), room allocation on the floor was based on mobility. This meant that if a new resident required a ceiling lift, or if a current resident had a change in care needs that necessitated a lift, these individuals were assigned to a room that could accommodate this requirement. The outcome of this prioritization was that in general, non-ambulatory people were assigned to one of the larger rooms available to a resident (single occupancy) and during the tenure of a person’s residency they were moved according to their changing mobility. This meant that a resident’s mobility and transfer needs took precedence over social concerns/needs, such as room location, size, or view preference.

**Technological Supports and Policy Changes: Impact on the Ground**

The use of a variety of technological supports enabled staff to provide care to physically challenged residents at Cedar Grove, yet the guidelines and recommendations around their use arose in this study’s findings as an area of ambiguity amongst direct carers. This second area of findings on staff safety came to the fore as an area that produced feelings of alienation and frustration in direct care staff.

One issue that demonstrates this is related to the use of sliding sheets or ‘soaker pads’ to reposition a resident in bed that has recently been challenged by a recent policy shift. Health and safety regulation identified this common practice of repositioning a resident using the “soaker pad” as a risk factor for injury and changes were implemented
This was raised by a number of carers as an issue. For example, one RCA, Inge
stressed the magnitude of these changes on RCA work, but also highlighted not feeling a
part of the decision-making process noting that this was a “massive change” that was
“dumped on us.” According to Inge, and others I spoke with about this topic, the result of
a lack of consultation with the people actually doing the work created dissonance
between organizational policy and the reality of the work. Specifically, the perception
that changes in practice guidelines “brought down” on direct carers by Cedar Grove, who
themselves were accountable to Occupational Health and Safety Regulation.

Data revealed how this and other changes in organizational policies left direct
carers feeling alienated from the process. This was important because they saw
themselves as the members of the care team most familiar with the requirements,
challenges, and peculiarities of the job and yet they felt ‘cut out’ of decision-making
around policy that directly affected their practice. RCA Meeta commented on this and
added an interesting twist; “I can help you [Cedar Grove] save money. I’m not joking. I
can see ways to save [Cedar Grove] a lot of money.” For her, a lack of RCA participation
in decisions around practice actually cost the facility money. Similarly, RCA Inge
emphatically stated, “They have to talk to the people doing the work, and that’s what
nobody does.”

“*There’s no time for kind, calm caring*”: Time Constraints and Workload

The third area related to findings on staff safety and practice regarded concerns
over the failure of the policies to reflect the demands of the job, most notably, with
respect to time constraints and workload. Findings revealed that time constraints and workload were issues that were closely linked with the theme of safety at Cedar Grove. Care staff expressed feeling challenged to fulfill their job requirements for any given day because of these two issues.

For example, RCA Minnie, a veteran staff member shares her concern:

EK: What challenges you in your role?

Minnie: Behavioral problems with the residents, time constraints, sometimes situations that you might run up against, time constraints and you find something that you’re going to having to spend an extra half an hour with because they made a mess or something like that, or are upset or whatever, before you can basically move on to the next resident and help them out. So yeah, that’s probably the biggest.

EK: So when you feel that way how do you deal with it?

Minnie: Well, usually I try and deal with it myself and if it’s impossible to and I’ve got something, a situation that I need help with, whether it’s unsafe, for the resident or myself, I’ll ask another staff member to come and help me. But I also say it’s hard to find somebody because they’re busy getting their resident assignment up.

As Minnie implied in this conversation, overwhelmingly, the view of members of the direct care team was that there are not enough hours in the day to do what they understood to be their designated job.

This relationship has been addressed in numerous recent studies of LTRC and quality of care through the issue of appropriate staffing for optimal care. There is
growing evidence linking staffing and quality of care in the province. Specifically, research links higher levels of direct care staffing to positive outcomes for residents and the overall work environment (Health Employees Union, 2009). McGregor and Roland (2011) state, “one of the most common structural measures of care quality is staffing levels” (p. 11). The issue of daily hours of direct care provided to residents in LTRC came to the fore during fieldwork with the release of the provincial Ombudsperson’s report (British Columbia, Office of the Ombudsperson, 2012). The Ombudsperson (Kim Carter) visited Cedar Grove to share highlights of the report. As this report detailed, there is currently no established, legislated, minimum of direct care hours (by RNs, LPNs, RCAs or registered psychiatric nurses) that a licensed residential setting must provide per resident per day (p. 110)9.

During data generation, Cedar Grove’s staffing level was 2.36 hours per resident per day and this was widely considered as less than optimal. Indeed, it was far below the Ministry of Health’s guideline listed in the Ombudsperson’s Report of 3.36 hours, a goal to be reached by 2014/15 (2012, p. 173). This number was also below that suggested by recent studies conducted in the United States which suggest between 4.1 and 4.5 hours of direct care per resident per day for improvements in quality of care (Collier & Harrington, 2008; CUPE, 2009).

For many direct carers, workload and time pressures were intrinsic to the job. In a conversation with RCA Nora, she shared the insight that all care is “time-centred.” For Nora, even at the time Cedar Grove was officially an Eden facility, she felt “pressed to work” (i.e., to complete her assigned tasks). To address the demands of the job related to

9 [A facility’s staffing level is calculated by averaging the number of paid hours per resident-day for every staff category (RCA, LPN, RN), divided by the total reported number of paid hours in that staff category (in that year) by the number of beds staff, all divided by 365.25 days (McGregor et al., 2010, p. 2)].
time pressures, direct carers developed efficiencies that allowed them to complete their care “assignments” in the parameters of his or her shift. However, when time constraints and workload intersected with the culture of safety, carers felt pressured to take “shortcuts” in order to complete their day’s work, as they understood it.

Several direct carers discussed how there were many times in their day when the stresses on their time, or the demands of their workload, were seen to conflict with organizational policy aimed at staff safety. For example, during fieldwork, there was a change in practice that related to caring for immobile residents. According to the new guidelines, two carers were supposed to participate in the task of repositioning an immobile resident in his or her bed through the use of a sliding sheet. In reality, this required an RCA to locate another RCA to work together to complete the task. This meant that the care routine would be interrupted as the RCA went to find assistance. Staff recognized that the rationale for the policy was that working together was the best way to avoid injury to the worker (and likely the resident). However, this directive meant that the task took more time, and time was at a premium for RCAs. The result of the timesaving approach of completing the move independently raised the risk of injury. RCA Sam sums up the tensions that existed around time constraints, workload, and safety: “There’s no time for kind, calm caring, I’ve figured out ways to do it safely, but you have to cut corners, there’s no time.” In another conversation, Sam noted the repercussions of the tendency to take short-cuts: “I always go home with a sore back.” Sam’s own well-being had been impacted.

As discussed earlier, the RCA Sam’s view that “cutting corners” on the job was rooted in a failure to consult with the people with the hands-on experience of providing
care. Therefore, expectations on how best to prevent injury were perceived as failing to consider the realities of the job such as time pressures and increasing workloads. In other words, organizational policy in this instance did not adequately reflect the demands of the job and as a result did not make sense to the direct carer. Therefore, in an effort to do their work, at least one carer felt it necessary to contravene organizational policy on staff safety.

Adding yet another component to understandings of the complexity of the web of time constraints, workload, and safety, was the tendency for staff to do for residents what they might still be able to do on their own. The tendency for carers to create passivity in residents by limiting choices and doing things for residents that, given support and time, they could do themselves has been accused of contributing to “excess disability” (Diaz Moore, 2004; Sabat & Lee, 2011) or “learned helplessness” in a resident population (Brooker, 2004; Ice, 2002). An RCA in this study raised this as an issue in her experiences providing care at Cedar Grove: “My thoughts are if we keep doing, because of time restraints, things for elders that they can (albeit slowly) do for themselves, they will stop trying.”

In the same vein, a family member talked about the impact of this practice on her aunt:

All the time I’m with her she goes to the washroom by herself. And I noticed one morning the care aides had cut up her waffle in little bits. And I know they do that for everybody. When I take her out she often orders a meal. She can handle her knife and fork just like you can. And I think that would bother her. But that’s
what they do and I can’t see them if they are cutting it for everybody, why do something different for her? You know?

Later in the conversation, she related this tendency to workload:

Then there is somebody over there trying to get out of the wheelchair that shouldn’t. There is somebody over here doing something. This one needs a change. And it’s…it’s hard.

In these quotes, the family member points out the safety imperative in the care culture. She also identified a potential correlation between over-caring and workload that have the potential to significantly impact the resident population, in part, by preventing residents’ use of retained skills. In combination, these quotes highlight that the quest to make the best use of limited time in effect have a negative impact on staff safety and residents’ well-being.

“Aggression” and “Violence”: A Vision for Prevention in Practice

The findings covered in this section focus on resident “aggression” and “violence” toward staff, a primary concern at Cedar Grove. In conversations with direct carers, many identified so-called behavioral challenges related to dementia as the source of potential injury and harm to workers. Care aide Minnie, quoted earlier, alluded to, “behavioural problems” in the resident population as a significant challenge in care practice that entailed threats to her safety. Her statements are consistent with other research. For example, as McLean (2007) attests, “In general, behaviours seen as problematic include those that may cause harm to the person with dementia or others…such behaviours would include both aggressive and non-aggressive verbal, vocal, and motor activity” (p. 22).
During fieldwork, administration estimated that people with a dementia diagnosis constituted 80% of the Cedar Grove resident population. Staff was cognizant of the general trend in residential care toward a greater percentage of the population living with dementia. Often, concerns around staff safety were associated with the provision of nursing and personal care to these residents with dementia; staff reported encountering verbal abuse and/or physical aggression in the form of hitting, biting, or scratching.

Measures were taken to protect staff. For example, one measure the facility employed to protect staff involved a visual reminder. A sticker, a red dot, was posted on the doors of residents who had a history of challenging behaviours in order to alert staff to the possibility of aggression. However, despite these measures, staff expressed the view that an expected part of their job was providing care for people who could respond to them with violence.

Interestingly however, staff did not feel that the violence was just related to the dementia diagnosis. Rather, there was some recognition that the potential for resident “aggression” and “violence” was related to workload and time constraints. That is, when a carer felt pressured to complete their work, they felt the conditions for violence toward them were set.

To address this, in part, Cedar Grove conducted ongoing educational and training sessions that encouraged staff to, as Fazio (2008) puts it, “focus less on what is done, and more on how it is done” (p. 156). With residents’ well-being in mind, administration articulated a vision that stressed the importance of how care is given, while recognizing the demands placed on direct carers. In this way, the likelihood of creating situations that produced aggression and violence might be lessened. In the following passage, an
administrator shared her thoughts on the substantial pressures carers face and how these pressures intersect with the organization’s vision for culture change:

And that’s all well and good, but you know what, I’m here with 10 people to take care of and they need bathing and toileting. So you can talk about it, but you know what, we take care of these people or the daughters are all going to be on top of us. So it’s how do I fit our vision of what has to be done? They’re right. So that’s the challenge. And that for me is about raising the bar.

This passage also demonstrates how the quest to “raise the bar” points to an important tension between administrators and direct carers around culture change issues that impinge on safety.

Through my various interactions with direct carers, I came to appreciate how, despite efforts from administration to contribute to an appreciation for, and the implementation of, more balanced (safe) care, members of the direct care team continued to experience considerable pressure. Interestingly, staff located the source of work-related pressure to “get the job done” in both leadership and co-workers. RCA Minnie commented on the complexity of competing demands in her role,

Yeah. And then you tend to get care-aids or whatever that, that are very into trying to go around and make everything wonderful and serve tea when you know they’ve got somebody that wants to go to the toilet. It’s such a fine line, sometimes between going overboard with the emotional and what not and neglecting your actual work which is you know, making sure people are clean and fed and clothed.
To her and other carers I spoke with, providing care in the context of culture change was fraught. It was important to direct carers that their peers not consider them to be “slacking off,” as an RCA described the situation to me. Direct carers highlighted what they understood to be, what Minnie described, as “actual work” as per their understanding of their job description versus the objectives of culture change that emphasize social care, alluded to as “serving tea.” This is a key finding because as Banerjee and colleagues (2008) identified, “the privileging of instrumental tasks over relational care work – have greatly contributed to the levels of workplace violence” (p. 2) in Canadian LTRC settings.

Another example from care practice of this vision-practice-safety nexus occurred during a care meeting. It was customary during the brief daily care meetings and the more comprehensive care plan meetings for a cross section of staff to address challenging behaviours manifest in certain residents. An illustration of this practice from my field notes concerned a resident of Holly Street. Bridget was a youngish woman with a moderate (frontotemporal) dementia and several chronic conditions that included arthritis and diabetes. Bridget was described as “resistant to care” and there had been several documented incidents of violence. On a daily basis, while providing care, RCAs encountered verbal and physical abuse from her. In this meeting, nursing staff, RCAs, and leisure staff conferred as a team about possible causes of Bridget’s discomfort, as well as some of the techniques to offset problems they had employed with varying degrees of success. Evidently her medication was under review by her physician. Together, they discovered that one trigger for Bridget was the involvement of more than one carer at a time. That is, when two RCAs were involved in providing care, Bridget’s
negative reactions were magnified. Someone suggested the possibility that she may have encountered a trauma in her life that contributed to her agitation and violent outbursts, though no one was aware of this aspect of her life history.

Regardless of the source, the consensus in this case, and other similar situations, was that resident violence was an expression of fear and confusion, and not a purposeful act aimed at hurting staff. This finding highlights an area of current research that promotes a distinction between understandings of aggression and other “dementia behaviors” as an inevitable outcome of neurodegeneration that accompanies dementia versus a psycho-social-environmental understanding. Whereas the former approach renders carers relatively powerless to improve the lives of persons with dementia, and in effect assigns blame to the person with the disease, the latter approach demand carers’ recognition of these behaviours as attempts at communication, namely as expressions of unmet needs (Hancock et al., 2006; Cohen-Mansfield, Libin, & Marx, 2007; Kolanowski & Whall, 2000; Kovach, Noonan, Schlidt, Wells, 2005; McLean, 2007b). In this light, carers can do a lot to prevent and/or manage resident behaviours that are often seen in the institutional care of persons with dementia.

Familial expectations represented another component of this issue. That is, adding another level to decisions around Bridget’s care was the expectation(s) of her family. Evidently her children had voiced many concerns over their mother’s physical appearance and hygiene. Staff expressed feeling pressure from the family in this regard. I learned later that after trying many combinations and permutations of staff and approaches during care, they had reached a solution. It turned out that when a particular male carer interacted with her everything “went smoothly.” A solution had been reached
that prioritized staff safety while also respecting the needs of the resident and her family. Knowing what caused the outbursts helped to avoid future incidents. This solution, as it was explained to me, came about through an appreciation for the complexity of the issues, support for role flexibility, and understandings of good dementia care.

Toward the end of fieldwork, I learned of a care event in which staff safety was compromised; an RCA was injured while providing bathing care to a resident. Cedar Grove encourages and indeed is legally required to report such incidents. Representatives from WorkSafeBC (Workers’ Compensation Board of BC) were on site, investigating the incident and offering support. Their role was to examine work practices that were linked to violence between residents and staff in order to identify what processes are, or should be, in place to protect the health and safety of workers. As a representative said, from their perspective, “health and safety trumps all.” This event illustrated yet another layer of monitoring and surveillance in LTRC in relation to safety.

Collective Safety: Outbreaks, Quarantine and Infection Control

The last section of this chapter will focus on an area of safety that I encountered which impacted the broader community of Cedar Grove—residents, families, staff, visitors, and students. Infection prevention and control emerged as an important part of the overall culture of care and safety.

The focus on infection prevention and control was visible from the moment one walked into the facility: hand sanitizer dispensers were located throughout the facility, and a sign posted in the foyer encouraged visitors to wash their hands prior to entering and before leaving Cedar Grove. During fieldwork, I was cautioned on several occasions
by carers to wash my hands after I interacted with certain residents, letting me know that they had an infectious agent that I should be aware of. As well, posters reminded staff to maintain good hygiene through hand washing. I observed housekeeping staff cleaning and buffing floors, equipment, and other surfaces according to a work schedule. Laundry was carefully handled to reduce or eliminate the possibility for cross contamination of residents’ soiled and laundered clothing and linens. As well, many of the smells that permeated the care floors were from cleaning products.

This aspect of safety was articulated in the organizational policies of the facility. For example, Cedar Grove promoted an “Elders Bill of Rights and Responsibilities.” Included in this document is the “right to live in a home-like environment that is clean and safe.” Similarly, Accreditation Canada (2010), as a part of their assessment, monitored “measures practiced by healthcare personnel in healthcare facilities to decrease transmission and acquisition of infectious agents.” Given the health status of the resident population, carers were encouraged to receive a yearly flu vaccination and these shots were available on site, without cost. As of the last review, there were no “unmet criteria” around infection control and prevention, though ACC suggested that flu shot uptake in staff could be improved.

Despite these prevention efforts, I encountered two incidents of disease outbreak. The first outbreak was short-lived and more localized in the facility. Both involved the spread of a type of norovirus that caused gastroenteritis—vomiting and diarrhea are common symptoms experienced by the afflicted. The result of this second outbreak on the Cedar Grove community was widespread. This outbreak entailed quarantine and the implementation of a series of measures to reduce spread. This meant five-weeks of
restricted access from visitors and the cessation of group activities for the residents of the care floors. By the time it was over, 70 residents and over 30 staff had been ill. Fortunately, this incident did not result in a death.

After five weeks, guided by a protocol on infection control the ban was lifted. Soon after, I visited the facility and learned that affected staff had recovered and returned to work. A number of residents talked to me about their experiences of the outbreak, sharing stories of its impact on their daily life. For example, resident Hannah, a highly social individual with friends in various parts of the facility stated, “It was awful, we had nothing to do…I stayed in my room and listened to the radio, and TV.” She was visibly relieved, now that “things have gone back to normal.” “We couldn’t do anything,” she reiterated, to which those seated around her nodded their heads in agreement. Hannah’s comments referred to the fact that during the outbreak, residents were restricted from gathering for social or leisure purposes in order to protect them from contracting infection. This lack of accessibility to leisure programming and informal social gatherings during the outbreak appeared to have had a negative impact on the psychosocial well-being of residents. In this way, residents expressed the view that adherence to public health guidelines superseded quality of life domains in resident care at Cedar Grove.

Chapter Summary

This chapter addresses the first important finding of this study related to safety as an organizational priority. The focus on safety at Cedar Grove had a wide-ranging impact on members of the culture of care. The physical layout of the facility presented particular challenges to staff in terms of ensuring resident safety. Data showed competing priorities
around resident safety related to administration and care staff understandings of the best interests of the resident versus the desires of the resident and/or family around safety and risk. Ethical considerations that sought to balance security and freedom were a part of the decision-making regarding resident safety in care. However, concern for residents’ physical safety emerged as the bottom line, ultimately taking precedence over other issues in residential care, such as quality of life. The most frequently cited threat to staff safety was associated with the physical demands of providing care to frail and often immobile residents, many of whom had dementia. There was also evidence of the primacy of collective safety in the culture under study, specifically, safety issues devoted to infection prevention and control within the facility.

Residents, their families, staff and administrators’ roles at Cedar Grove were shaped in disparate and at times overlapping ways by the imperative of physical safety. At times, residents and staff confronted safety in a manner that reflected their respective roles and/or daily experiences. At other times, safety issues overlapped and bridged the roles and day-to-day interactions of members of the care culture. There were instances when the objective of safety clashed with constituents’ needs and desires as well as understandings of organizational practice and individual’s autonomy and rights. Overall, there appeared to be a struggle to balance the needs and preferences of residents and families, staff roles and responsibilities in practice, and leadership’s vision for culture change as expressed through a philosophy of care that simultaneously endeavoured to prioritize social aspects of care.
CHAPTER 7:
CULTURAL PERSPECTIVES ON CARING: THE SIGNIFICANCE OF
RELATIONSHIPS AT CEDAR GROVE

Approximately nine-months into my fieldwork, having spent considerable time
with residents, families and staff members in my quest to understand Cedar Grove’s
culture of care, I documented the following interaction with Augusta, a resident of
Juniper Way:

Augusta was seated in her wheelchair, lined up against the wall, waiting to be
escorted down in the elevator for her lunch. Blue bib already on in preparation for
lunch. On this day she was dressed in a flowered housedress with a long gold
chain, her white-white hair done to perfection. When I walked by her in the hall I
touched her arm as I greeted her because I know that her vision is poor. We had
then had the following exchange:

EK: Hi Augusta.

Augusta: You know me? [Eyes searching, as she grabbed my arm.]

EK: I know you Augusta.

Augusta: Good, great.

Her relief was palpable—I felt her relax—“Someone knows who I am” she
seemed to consider, a thought that gave her great consolation. Reassured, we went
on to talk about her upcoming meal and what her food preferences are. For me, a
bell went off; that’s the crux of it I thought. Augusta’s comments helped me to
crystallize something that I had been mulling over throughout my fieldwork—not
just the importance of relationship in dementia care, but also the nature of relationship. Her words made me acutely aware that although I am not someone Augusta remembers from day to day, we meet at a place of a different kind of knowing. In this exchange, the fact that I know something about her is comforting to her—someone knows who she is and is able therefore to make her feel safe and draw her out into the social world of Cedar Grove.

Many months later, when Natasha, a resident of Holly Street, returned my greeting with exactly the same response I was struck by the power of the phrase. “You know me?” she replied when I said “good morning Natasha.” Thinking about this more deeply, I tried to understand the meaning of these interactions in caring for persons with dementia at Cedar Grove.

It was in this light that I documented an exchange between nurse Evelyn and resident Violet. It began with Violet trying to get the attention of Evelyn, who was behind a desk doing paperwork:

Evelyn: Violet, go to your room, wait for me, I just have to finish this and I will go to you.

[Violet remained.]

Evelyn: I told you to go to your room, wait for me, wait for me Violet [she spoke lightly and kindly.]

Violet: Okay. [Seconds later]. Well I'm gonna ask you for the key.

Evelyn: I've got the key.

[Almost immediately.]

Violet: Are you done yet?
The nurse gets up and puts the binder she was working on away on a shelf.

Evelyn: There you go Miss V. Wait for me...

[They walk toward Violet’s room together, hand in hand] [6:45 am, 06/30/11]

As I witnessed and transcribed verbatim the above interaction, I struggled to figure out how to portray the complexity or subtlety of this exchange in field notes. I thought that it illustrated some of the many challenges, and rewards, that direct carers encounter on a daily, if not hourly basis. It reveals the well-documented demands of paper-work versus people-work that exists in residential care. On paper, this encounter might come across as Evelyn acting dismissive of Violet; in reality, it had a categorically different affective impact on those present, including me. It also struck me as a moment in care when a staff member connected with a resident at a relational level. Without superficial niceties or undue force, Evelyn was able to attend to her contradictory tasks at hand—paperwork and engaging with Violet. More than this, it communicated the fact that Violet was responding to more than the rational content of Evelyn’s message and felt validated in the exchange. This one episode reminded me of how easy positive interactions could be and how difficult this is to document or codify.

This chapter presents findings on the significance of relationship at Cedar Grove. In the previous chapter I discussed the safety imperative and its multifaceted influence on the culture of care at Cedar Grove. This organizational priority was influential in shaping the social world of the facility and for creating the conditions in which relationships might develop and be sustained. Given the “social nature of human life” (Kitwood, 1997, p. 83) and the importance of relationships in a “new culture” of care versus an “old culture,” demarcated by Kitwood (1995/2007), how relationship is experienced by
members of the care community indicates a great deal about the culture change underway at Cedar Grove. It might be argued that the success of the organization’s transformation hinges on its ability to help meaningful relationships flourish. As members of a residential care facility fully engaged in a process of culture change, residents, families, staff, and administrators all spoke about a desire to develop quotidian relationships and the challenges involved.

Because residents’ perceptions and experiences are crucial to transforming LTRC, I first present findings on relationship in care from the perspective of residents. In conversations, residents expressed the desire for relationships not only with carers, but also with other residents. In addition, observational data revealed the positive impact on care that might be described as relational on residents with moderate to more advanced stages of dementia. Next, I explore staff perspectives on relationship in care. This data highlights aspects of practice and policy that staff considered to either facilitate or impede their ability to deliver care in the context of relationship. I then detail findings on organizational support for relationships as an aspect of the culture change process. Finally, family perspectives on relationship are addressed that highlight the importance of positive interactions with staff carers, depicting it as a critical for their own well-being as well as that of their relative in care. However, despite important benefits, there was a scarcity of familial involvement in care. In this discussion I also consider the social and organizational factors impacting family participation at Cedar Grove.
Resident Perspectives on Relationship in Care

Residents clearly communicated the meaning and significance of relationship with carers in a variety of ways. Spending time on Juniper Way, I found that many people wanted social connections with the people who care for them and that such a connection was vital to their well-being. I also witnessed many instances of staff joking with, hugging, guiding, and comforting residents while providing care. Other times, I witnessed staff who were pressed for time failing to meet resident needs for social connection. These interactions appeared to have a negative impact on residents as demonstrated by their verbal protests and non-verbal signs of ill-being, such as agitation, withdrawal and bodily tension (Brooker & Surr, 2005). Many residents shared the meaning and impact of an absence of such connections with carers in their daily life. For example, in an interview with long-time resident Hannah, I learned that even a mundane activity could have important social meaning for a resident:

Hannah: There was one nurse that uh, I really looked forward to her when she came with the evening medication. We talked about everything and she was so relaxed. Now, everybody’s in such a rush...you know care people have a lot to do.

EK: Right. So you feel they don’t have the time for conversation?

Hannah: No. I can realize you know the pressure they’re under. You know they have to get people into bed by a certain time and, and they really need more staff.

Hannah understood the necessary task of getting people to bed on time and its strain on direct carers. More than this, she remembered a time when she had been able to enjoy a chat with a carer who was less burdened by workload. She recalled anticipating conversations with a specific nurse during a daily care encounter. When Hannah referred
to the present at Cedar Grove, she characterized her understanding of it in terms of increased workloads and time pressures for carers. Many other residents of Juniper Way shared Hannah’s perception.

Hannah’s story is important because it suggests a contrast to current care. It points to a time gone by when, in her opinion, nurses were more “relaxed” and able to be more generous with their time. When asked directly if she felt like she had a relationship with staff Hannah was resigned: “Well, since I’m more or less independent, I don’t see much of them. I don’t need anything.” Hannah offered her independence as a not entirely satisfactory excuse for the situation.

In an interview with another Juniper Way resident, Ruth, the dearth of opportunities to relate to staff was also presented as a problem. Ruth began our conversation by recounting how she struggled to raise and feed a large family. Ruth’s family was great source of pride for her and her room was loaded with their photographs. Thinking about the potential raised by these personal photos, I asked her if she enjoyed a relationship with direct carers. She replied, “No. They’re too busy. Here in this building they are too busy. They have no time.” Ruth elaborated on this perspective:

Ruth: Now look I come in this room, and there is nothing. They don’t talk back to me. You know?

EK: When the care-aides come in they don’t converse with you?

Ruth: No.

EK: So when people come in here, they don’t look at your photos or--

Ruth: No.

EK: --or talk or?
Ruth: Of course not. It’s too…it’s nothing to them.

Both Hannah and Ruth felt that staff were too “busy” to offer meaningful social engagement. It seemed, from Ruth’s perspective, that her attempts to connect with carers through conversation were not reciprocated. She despaired over a lack of rapport with carers, stating that it was “nothing to them.” Ruth further revealed, poignantly, her thoughts on care and relationship or lack thereof, in this excerpt:

EK: Is there anything you think could be added to the care here that would make a big difference for you?

Ruth: [5 second pause] I am alone in this you know, and when there are more people, and I’m not so alone in this, makes a difference.

In addition to residents’ perceptions of the overall “busyness” (Innes, 2009) of staff as detrimental to the formation of relationships in care, resident Maria added another insight into practice. Maria referred to care that lacked the element of collaboration, of what could be described as a partnership in a care encounter. This is apparent in our discussion about her daily routine:

EK: Okay. So they get you up at 8:00 and then what happens?

Maria: Well they dress you.

EK: Yeah. So they help you get dressed and wash up I guess.

Maria: They don’t help you. They do it.

EK: They do it. Okay. Is that okay with you?

Maria: I guess so, yeah.

EK: Would you rather participate in that more?

Maria: No I think it’s okay.
EK: It’s okay. So you pick out the clothes you’re going to wear or?

Maria: They do. I let them do it I don’t know, I never questioned it, so I just let them do it.

Maria’s comments highlighted her perspective on a lack of participation in aspects of her own care. She seemed resigned to having everyday decisions; in this case, what clothes she might wear that day, made by others. However, unlike Hannah and Ruth, Maria took personal responsibility for her lack of connections with staff. Rather than locating barriers to relationships in organizational pressures and practices, as they did, Maria maintained it was her fault. Her interpretation of this situation was in keeping with her stoic resolve, witnessed on a number of occasions. Maria stated, “I’m not particularly, I’m not a particularly pleasant, useful participant when it comes to talking or anything so I’m not very good at it.”

Juniper Way residents expressed a desire to have a relationship with carers, to chat with them, to know something of their life and vice versa. Many felt that at present, care staff were stretched for time and that the demands of their work interfered with their ability to engage in conversations, and consequently, to form relationships. Likewise, the residents I met in the Holly Street SCU conveyed a similar desire to be-in-relation with others.10 While Holly Street residents were not as able to verbally communicate their relationship needs or the levels of satisfaction with Cedar Grove’s social care, the situations I observed suggested that, like residents on Juniper Way, individuals in the SCU were eager

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10 Because Holly Street residents were more likely to live with a moderate to advanced dementia and experienced a range of communication challenges, my findings from the SCU are reliant on PO, which included informal conversations, and DCM sessions.
for attention from carers.

In PO and through informal conversations, I witnessed many examples of residents employing a variety of strategies to communicate with staff and each other. For example, residents used short verbal comments or responses. In attempts to get someone’s attention or to connect with a staff carer, they would say, “No,” “Thanks dear,” “You’re lovely,” other terms of endearment, or whatever words they might find. Often, the phrases voiced expressed residents’ gratitude. Other residents, with less access to words employed non-verbal strategies, using a sound, like a murmur or harrumph, to invite contact or to respond to a situation. Frequently, attempts to make eye contact with another resident or carer accompanied these sounds. Eye contact attempts were not always successful, but when they were, I noted that another resident or staff person would often respond and the result would be an interaction with the resident. Certainly, these attempts worked with me: when a resident made eye contact with me I was drawn to interact with them. Other types of communication Holly Street residents demonstrated included gestures, head movements, touch, smiles, hugs, and other expressions of warmth.

When they failed to get positive attention, Holly Street residents were also observed to express anger, frustration, and displeasure with staff and other residents. Residents would vocalize their discomfort or displeasure and even yell loudly across the room: “No!” “That’s mine,” or “Get away!” Residents also used nonverbal forms of communication such as frowning, grumbling, lashing out or slamming an object like the table or a chair. Interestingly, unlike responses that
came about through the confines of a formal interview, these words and gestures, both positive and negative, were offered spontaneously, unprompted by formal questioning. And as such, they give a reasonably accurate portrayal of social care in the moment. Findings indicate that residents of the SCU demonstrated a desire for, and seemed to benefit from care practice that occurs in the context of relationship. This is consistent with Tuckett’s (2007) study of “health care provider-older person relationship,” which suggests that communication is the foundation for “all aspects of a relationship between people” (p. 80). Snyder (2006) also contends that the “need to communicate and to be understood is fundamental to the human experience” (p. 259).

**Dementia Care Mapping Data on Relationships in the SCU**

Whereas interviews and conversations with residents helped reveal a desire for recognition and social interactions, DCM data highlighted and provided detailed information on important aspects of social care for residents who were unable to verbally communicate their needs. In this study, the method of DCM (University of Bradford, 2005) was instrumental in gaining insight into both the scope and quality of interactions between staff and residents with dementia and the social world of Holly Street. In total, I conducted 24 hours of DCM in the SCU on different days of the week, at different times of the day. Five residents were mapped per session (8) with a total of 19 residents observed from 3 – 14 hours each, averaging six hours of mapping per resident. All sessions were conducted in the common area. Findings from DCM (quantitative and qualitative data) provided numerous examples of care interactions that highlighted care encounters, and interactions between residents, that demonstrated the presence of
relationship. This data also highlighted the long periods of time when some residents were alone, unable to initiate interactions with others, and the negative impact of this social isolation.

**Quantitative Data.** The quantitative data generated through DCM highlighted the range of behaviours, moods, and levels of engagement of residents in relation to the care and social environment of the common area of the SCU. Group data is illustrated through the Well-Being/Ill-Being scores for each DCM session. These scores range from -5 to +5 and indicate the extent to which an individual is in a state of well-being or ill-being in each 5-minute time frame.

This data showed that residents on Holly Street were in what DCM refers to as a +1 state of mood and engagement (ME) for 82% of the time they were observed. According to DCM operational rules, this value is used to describe a person in a “neutral” mood, with an “absence of overt signs of positive or negative mood.” With respect to engagement, this value also describes a resident who is observed to be “alert and focused on surroundings” with “brief or intermittent engagement” (University of Bradford, 2005, p. 13). Therefore, the data showed that much of the time, residents in the common area of the SCU were passively engaged in their surroundings, watching but not directly interacting with anyone.

Although many of the time frames that were given an ME score of +1 did not include interactions with staff and/or other residents, some did. Of these, residents' behaviours might have included interactions with another resident, verbally or otherwise, or their involvement with a direct carer (coded A – for
Articulation Behaviour Code Category). Examples of behaviours that involved interacting with others that were coded as +1 included, for example, a carer assisting a resident with a meal (F +1- for Food BCC) or administering medication (P +1- Physical BCC). For a table of the range of behaviours mapped and percentage of time BCC was recorded, see Appendix D. This data then suggested that the existence of resident-resident or resident-staff contact alone was not sufficient to improve the mapped residents’ mood and engagement.

Rather, ME scores increased for SCU residents when they interacted with others. The data revealed that for 6% of the time mapped, residents were in a +3 state of mood and engagement. According to DCM operational rules, this value describes a resident’s mood when they appear “content, happy, relaxed” with a “considerable positive mood,” or a person who is “concentrating but distractible” with “considerable engagement” (University of Bradford, 2005, p. 13). During one session, a visit by family members to the SCU had a measurably positive impact not only on the resident relative, Gerta, but also on another resident, Fran, who joined in on the visit in the common area. During the visit, Gerta enjoyed seven, 5-minute time frames, of A+3 (A – Articulation BCC) while Fran scored four consecutive time frames of A+3. During this visit the three women laughed and chatted. Interestingly, Gerta and Fran do not speak the same language.

Another prolonged period of +3 ME was correlated with a self-initiated, sustained conversation (A – Articulation BCC) between two residents. These two women discussed one another’s jewelry, pointing out one another’s rings and sharing necklaces while displaying considerable engagement for 25 minutes of the time
observed.

The highest level, a +5 state of mood and engagement was recorded for less than 1% of the time mapped. According to DCM operational rules, this value is used to describe the mood of a resident who is “very happy, cheerful” with a “very high positive mood” and who is “very absorbed, deeply engrossed/engaged” in their environment. The example from the data that demonstrated the highest level of ME score involved an interaction between Eva and a direct carer. I wrote the following note about this interaction:

Eva spent 23, 5-minute time frames (115 minutes) passively engaged with no signs of positive or negative mood for 64% of the time mapped today. During the music program, her ME score rose to +3 for four time frames, or 11%. At times her hands shake and her mouth opens and closes, her tongue moving in and out in a lapping motion. She also makes a “dah, dah, dah” noise while she moves her head and eyes, watching others who are active around her. Her hand was in her mouth for one time frame, and was scored a W+1 for 3%. At 10:00 am, after 30 minutes of passive engagement, a direct carer came in and hugged Eva, made eye contact with her, addressed her by name, and with a tone of celebration told Eva about the upcoming activity. The result on Eva’s ME was profound. In response to this interaction, Eva said some words and lit up with eyes shining, moving her legs around with excitement. She appears exuberant. The carer also appears to be cheerful and uplifted. For this time frame Eva scored an A+5, or for 3% of the period mapped. Eva was helped to eat for
three time frames, scoring F+1 for 8% of the time. While at the table, the RN cut Eva’s nails and later she was moved over by the window to have her toenails cut, scoring P+1 for 11% of the time. Overall, Eva was in a state of well-being of +1 for 86% of the time, and +3 for 11%, and +5 for 3% of the time observed today.

This excerpt provides data on Eva’s interactions with her social environment, as well as the impact of these experiences on her mood. From this, the type of care encounter that had a significant impact on Eva’s well-being is evident. Eva was addressed with physical warmth and her identity and preferences were acknowledged, which made an appreciable difference in her affect, thus contributing to the evaluation of this exchange as +5. The result of this brief, yet powerful interaction had an extremely positive influence on the mood and engagement of this resident. Notably, the carer appeared to be elevated by the interaction as well.

Group data also revealed times when residents were observed to be in a negative state of mood and engagement. In the language of DCM, a negative is used to show signs of “disengagement” when the resident is “withdrawn and out of contact with their surroundings” (University of Bradford, 2005, p.13). According to DCM operational rules, -1 ME value describes a resident who exhibits “small signs of negative mood” and whose engagement is “withdrawn and out of contact” (University of Bradford, 2005, p.13).

Residents of the SCU scored an ME value of -1 for 12% of the time mapped. No -3 or -5 ME values were recorded during sessions. Looking at the
data, residents’ who appeared to be disengaged with their environment were most often faced with an absence of activity or staff presence in the common area. For example, during one session, a resident who could be described as requiring extended care, scored a C-1 to describe “Cool” behaviour when she was disengaged, withdrawn (University of Bradford, 2005, p. 17) for 11 time frames, or 55 minutes. During this time, she was not watching anyone or anything, she was slumped over in her reclining chair, and from her posture she appeared to be slightly uncomfortable. Her ME score was eventually elevated following this prolonged period of disengagement when a nurse approached the resident to offer physical care.

**Qualitative Data.** In addition to the quantitative data, qualitative notes taken during DCM sessions on Holly Street provided valuable contextual information on the experiences of residents in relation to care practice and the care environment. From this data I discovered that staff used a variety of approaches and techniques to care for residents in ways that reflect a significant concern for relationship. Using DCM guidelines to interpret the quality of these interactions, I discovered many examples of what Kitwood’s (1997) Positive Person Work framework referred to as Personal Enhancers (PE). Specifically, Kitwood (1997) detailed certain types of care interactions that had the potential to create positive feelings and enhance the lives of persons with dementia. As described in DCM (8th Edition), I observed skilled and creative carers engaged in meaningful interactions with residents that had strong positive outcomes (Brooker & Surr, 2005).

Following DCM guidelines, PEs were employed to mark and describe
interactions that were most likely to promote well-being in residents. Here is a
description of a care encounter derived from notes on a mapping session that I
conducted on Holly Street:

RCA Lena approached resident Estella who was seated in her wheelchair,
head in hand. Lena was smiling as she crouched down beside her, touched
the resident’s arm, made eye contact, and said in a kind manner, “Estella is
it okay if we go for a bath?” In response to this question, Estella offered a
small hug and replied, “fine” in a warm tone. The two left the dining
room, chatting with one another as they went.

This was a remarkable exchange; I had often seen Estella adamantly decline
offers of support and was happy to see her accept Lena’s assistance. According to
DCM rules, I recorded this exchange as a PE of collaboration and warmth, which
helped Estella obtain her need for occupation and comfort; two of five
psychological needs of persons with dementia (Brooker & Surr, 2005). Overall,
this interaction was considered to be positive because the resident was consulted
and addressed as if she was a partner in the care encounter, as opposed a non-
person or a task. Also, the carer’s use of physical affection and caring affect
helped convey to the resident the good feeling that she was cared for, helping to
quell any fears. These data then provide insight into an approach that Estella
responded well to, as an individual.

Another example from the DCM data that illustrated staff concern for
relationship in care occurred when nurse Sam helped resident Annie eat her
breakfast. As Sam spooned the food into Annie’s mouth, she spoke to her about
various aspects of Annie’s life history and accomplishments. Annie followed the conversations with her eyes, appearing to listen to Sam intently as she finished her meal. In this way, the nurse conveyed three Personal Enhancers that included: celebration, acknowledgement, and recognition. Therefore, according to DCM rules, this interaction was considered to fulfill this resident’s psychological need for identity, attachment and inclusion (Brooker & Surr, 2005).

These examples from the DCM data indicate that staff engaged with residents in particular ways that suggested attention to care based on relationship. However, there was also evidence of staff interacting in less than positive, and even negative ways with residents. In DCM terminology, these encounters are described as Personal Detractors (PDs). These types of interactions on Holly Street, though far from a normal occurrence, might be considered to detract from the quality of care that is offered in the context of relationship. An example from the data of this type of interaction was observed between resident Eugenia and a direct carer Nora who was covering the social area of the SCU. Eugenia had a habit of calling out, “yee heee,” continually, until someone responded. During one mapping session she called out repeatedly and the direct carer snapped at her:

Eugenia: “Yee heee,” “yee heee,” “yee heee.”
Nora: No, “yee heee,” I have a name.
Eugenia: What’s your name?
Nora: Don’t you know my name? It’s Nora.
Eugenia: Nora.
Nora: Thanks, yes, that’s my name.
Here, not only were the carer’s words and tone of voice infantilizing, which undermined Eugenia’s need for identity but unlike the exchange discussed in the opening of this chapter the resident was frustrated by the interaction and appeared upset by the carer’s response to her. As is evident in DCM, in responding to Eugenia’s pleas in this manner, Nora failed to provide for her comfort needs. She demonstrated a PD that is known as withholding – as in “refusing to give asked for attention, or to meet an evident need for contact” (University of Bradford, 2005, p.73). This PD is also significant for its inability to contribute to relational care. Eugenia was not happy with this interaction and did not stay silent for long. It is important to note that this type of interaction, that might be described as evidence of malignant social psychology (Kitwood, 1997), where people are “demeaned and disregarded” (p. 4) was rare in the data.

The point of this section is to highlight the importance that residents placed on relational connections with staff. Relationships however are didactic and require the involvement of two people. Next, I would like to expand understandings of relational care from the perspectives of staff carers.

**Staff Perspectives on Relationships in Care**

A couple of residents here have gone through some psychological issues and I’ll even leave my floor to come up here, because I have a relationship with them and somebody’s said, “Meeta, so and so is upset, can you come and talk to them.” I think it is just being in this profession, you’re supposed to be caring about people. You are, but not everybody I work with is like that and not everybody has that in them to give. So sometimes it falls on one person’s
shoulders because nobody else working that day is that type of person to go and give a hug or whatever. [RCA, Meeta]

So I do really, really try to treat the people here as my family. Some people annoy me more than others, some people I love more than others. But I do, you know, they definitely make me a better person. They definitely, they bring out the best in me, I’ll tell you that. [Leisure, Sally]

Throughout this study, in many different ways, staff reflected upon the importance of connecting relationally with residents. In this section I draw together data that were generated through PO, individual, and group discussions regarding staff opinions on care based in relationship. I begin with a discussion of staff responses to the DCM data. Next, the data on staff-identified organizational practices and policies that functioned as barriers to relational care will be explored, primary among them being those associated with the adoption of a computer-based system of care planning. I then develop the findings pertaining to organizational support for culture change and conclude with data on the perspectives of family members around relationships and residential care.

**Dementia Care Mapping Data: Staff Perceptions of Implications for Practice**

In addition to conversations and interviews with direct carers, I participated in a series of daylong group meetings, held over a nine-month period during fieldwork that focused on culture change and direct resident care. Organized by Cedar Grove as part of their culture change process, these meetings
involved staff from each care floor and from a range of roles in the care team—administrators, RCAs, building maintenance, dietary, leisure, and a few family members. This was very useful to me as it helped me better access multidisciplinary perspectives on the challenges and rewards of care practice. As part of my role in being invited to attend, I presented data from my DCM sessions. Following these presentations, I asked staff to fill out an evaluation form (See Appendix C). This feedback enabled me to generate additional information on their perceptions and interpretations of the data presented, and to further explore some of my emergent findings.

While in each session carers listened to all of the DCM data, they responded most positively to the DCM data that illustrated the type of interactions that resulted in improved resident well-being. These meetings demonstrated the ways in which this observational tool might help “raise awareness of collective care practices” (Innes, 2002b, p. 34) including increasing understandings of the experience of persons in more advanced stages of dementia.

Three interrelated issues emerged in these discussions that seemed to resonate most significantly with carers and that generated the most discussion across groups: 1) Recognition that brief interactions are better than no interactions; 2) Recognition that carers can ”make a difference”; and, 3) Issues around personalizing care.

Supporting the importance of even brief interactions, the DCM data effectively demonstrated that many residents spent long periods of their time not interacting with anyone. It also revealed that personalized care encounters, even if
they were brief, still had a measurable positive impact on the well-being of the resident. In all of four group discussions with carers from each of the care floors, people talked about how this data countered a commonly held assumption. Prior to these discussions, direct carers seemed to believe that in order to connect with a resident in a meaningful way they had to allocate a considerable amount of their resources to the interaction. Many shared the view that they had thought that they had to invest significant time and energy in a prolonged encounter with a resident in order for it to be useful, i.e. contribute to residents’ well-being.

Given the staff concern over increased workloads and time constraints, this new knowledge was welcomed and offered ways of thinking about how to engage or relate to residents as carer staff went about their work. One participant said, “Using short periods to connect with elders [means I] don’t have to avoid because I think it has to be a long interaction to be good for elder.” Similarly, another direct carer interpreted this finding as impetus to change her practice; she said, it “challenges me to make the time to spend a few minutes with isolated people.” Yet another participant summarized feelings about how her work will be impacted by the understanding that brief encounters were capable of improving residents’ well-being by stating emphatically that the idea “actually makes me more aware!”

The second important issue that emerged through discussing the DCM data was a validation to carers that they could, and indeed did, make a difference. Carers shared how data and findings from my DCM might contribute to thinking about their practice because it illustrated the potential of their interaction to
improve residents’ well-being in a quantifiable way. An RCA stated, “It helps to do more positive things. Being able to see how person’s interactions can reach +5, I am even more motivated to interact with them.” Similarly, a care aide commented, “You become more aware of these little gestures that you do and doing that will help your work be easier and residents more calm.” Another suggested how this data “encourages me to give my best so I can make Elder’s happy and content.” Likewise, another carer commented on how her work will be impacted, “Looking at having interaction and how it affects the elders. Am I doing something beneficial or just maintaining the status quo”—the obvious inference was that she would choose positive change or the status quo. These insights point to staff understandings that connecting with residents with dementia as persons is a vital component of their caring role and that they are capable of making a difference, and that this difference is measurable. Moreover, as expressed by one RCA, it entreats carers to strive to provide care that surpasses their existing care practices.

The third issue that came out of presenting the DCM data regarded the importance of carers’ use of residents’ biographical information in care interactions to foster residents’ well-being. The DCM data illustrated that elevated ME scores were associated with interactions that acknowledged residents’ identity. When carers used a resident’s name or recalled their personal history or personal preferences, staff was able see how this made small, but positive changes to their care delivery. In response to this, direct carers in each of the four groups spoke about the challenges they faced delivering care that reflected residents’ life
histories. They indicated the many hurdles they encounter in providing care to residents that reflected their unique histories and personalities. In the words of one RCA: “We need to have elders’ history/life be known to all.” There was a widespread opinion among direct carers that they lacked vital biographical knowledge of the resident, knowledge they felt they could/should incorporate in daily care practices.

Discussion around the use of biographical information revealed an area of tension between staff and administration. Staff understood administrative expectations of culture change to involve more personalized care, and yet they saw that organizational impediments, such as access to computers and resident histories, detracted from their ability to engage residents in relationship. Specifically, direct carers contrasted administrative expectations of personalized care with a shift in care plan practices that prevented their access to residents’ biographies or life histories.

Findings from these meetings confirmed important issues that came up during one-to-one conversations. Direct carers complained about changes in documentation practices at Cedar Grove that served to distance them from residents’ life histories. Specifically, they identified computer charting as a barrier to their access to, and use of, residents’ care plans in general and life histories in particular. Like many long-term residential care settings, Cedar Grove transitioned from paper charts to a computerized charting system, the Resident-Assessment Instrument-Minimum Data Set (RAI/MDS). This standardized system was made available through GoldCare, a healthcare information management
software system used by residential and long-term care organizations 
(http://www.mygoldcare.com) and it provides the framework for comprehensive 
assessment and care planning for the resident population. Although designed to 
simplify the process, direct carers identified the standardized process that is 
associated with the RAI/MDS care, to “e-files,” as a significant barrier to carers’ 
access to residents’ biographical information.

The root of the barrier as described by direct carers was located both in the type of 
information gathered and the required use of a computer interface. With respect to the 
type of information gathered, carers commented that there was less personal information 
available. They also found the new care plans to be inaccessible. In the words of RCA 
Lena, “it totally excludes us from access, completely.” Unlike the profiles that used to be 
included in paper charts, which were most often narrative-based summaries of personal 
information, the RAI/MDS system was perceived as more medically oriented and 
narrowly restricted important aspects of the resident’s personality, life history and 
psycho-social needs. A nursing staff summed up many carers’ opinions on these charts 
when she lamented their lack of narrative, and stated, “It’s all tick boxes.” As it turned 
out, the use of computers had a significant impact in care planning and practice and the 
ability for the organization to support relationships, particularly with respect to the RCA 
role on the care team.

Exploring the Digital Divide: Computer Access, Literacy, and the Role of the 
RCA

At Cedar Grove, computer usage was clearly delineated by job categories on the 
care team. Administration, Registered Nurses (RNs) and Licensed Practical Nurses
(LPNs) used computers to access and update residents’ records and to communicate with one another, and families, via email. Leisure staff used the computer for leisure assessment and for email communications. However, the use of computers by RCA’s had not yet solidified during the period of my fieldwork. Residential Care Aides encountered barriers to computer use; specifically they did not have access to residents’ e-files. They lacked the computer skills and training necessary, and there were few if any computers available for them if and when they found time to look up information. In addition, confusion between RCAs around their job requirements and e-files emerged as a barrier to the care culture and positive culture change.

Several of the RCAs discussed the transition to digital records. For example, one long-time employee indicated that, “In the past care aides could read social history now that’s not accessible for care aides.” The comment was echoed by an RCA who declared, “now that it’s on the computer, I no longer use it.” Yet another RCA expressed similar problems associated with access to a computer terminal. In this passage, RCA Meeta added her observation of time investment and computer use:

So even if we could go to the computer to look at GoldCare, we only have one computer at the nursing station and either the nurse or the LPN, one or the other is always on it. And then the one down at the other end, if you do get on it, it’s so slow…it probably takes ten or fifteen minutes before it loads everything and by that time you get a bell and you have to go.

This quotation points to a structural confusion around care roles and the use of or access to e-charts. There was a perception that some staff are more entitled to the computer terminals than others. There was also a lack of clarity among RCAs on e-charts in
relation to the description of RCA roles and responsibilities. RCAs reported that no time in their shift was allocated to access e-charts, suggesting that this task was something extra a carer might do while on a break. RCA Lena described the challenges e-files presented. She detailed how the standardized format interfered with her ability to access residents’ histories, and therefore, her ability to personalize care:

Well it totally excludes us from access, completely. And, we used to be able to look at the chart, look at what somebody’s background was for example, if they were screaming in the shower we might be able to look at if they had a traumatic incident and what happened, or if they had violence in their house or work. If they are afraid of this or that, or what they like to do, because quite often you could trigger some really happy memories, to recreate some happy times. We don’t have access to any of that anymore.

Another RCA referred to the computerized system of charting as a barrier to her understanding of residents’ medical needs, she commented:

It used to be that I could actually go to the chart and see, if I noticed a rash on somebody and the nurses knew the next day, and I could go and see if the doctor, what they wrote about it…but yeah, it really is, it’s hard to have any information about people.

This final comment was echoed in my discussions with many other RCAs. As a whole, RCAs conveyed the opinion that e-charts interfered with their ability to access resident information. This situation interfered with their ability to integrate residents’ biographical information into their care practice.

My fieldwork occurred at the tail end of this institution’s transition from paper to
digital records. Leadership was well aware of the gap that existed between direct carers’ computer skills and the requirements of the RAI/MDS system. Also, administration identified the need to address this gap as essential to their culture change process. In the words of one administrator, “They’re [RCAs] missing half the flavour and they’re a part of the team. So that’s the plan. Talk about culture change right?” She recognized the difficult task ahead and with the other administrator sought to empower RCAs via participation in this crucial aspect of care delivery by providing computer training. Preparation for GoldCare use began with direct carers’ training on communication through email. Once a level of competency was reached on email, carer education would proceed to include the skills necessary to read care plans and support a record of communication between the care team via email. This training plan was in its early stages when I completed my time in the field.

**Job Descriptions: The Duties and Responsibilities of the RCA**

Through conversations with direct carers I recognized a source of tension that was, at least in part, due to interpretations of job descriptions. Specifically, there were some discrepancies in understandings of what duties and responsibilities might be associated with the job of RCA. RCA Minnie summed up a perspective held by many staff:

EK: So can you describe for me your role here?

Minnie: My role here is to make sure my residents; my side of the residents is cleaned, dressed, fed, basically maintained for my 8 hours here.

EK: When you say “my residents,” what do you mean by that?

Minnie: Well we all have sides, so depending on how heavy the sides are, I’ll
have 5 to 10 residents that I have to dress and wash and make sure, make their beds, and make sure that they get down to breakfast and that on time, or lunch or whatever the case may be, toileted.

Minnie was highlighting a key aspect of her job description, which although it names social aspects of care, presents the first duty of the RCA as assisting residents with the physical tasks of daily living.

Of course, it is overly simplistic and misleading to suggest that RCAs stuck to this description, without giving any value or time to social engagements with residents. As I noted previously, many times I witnessed Minnie and her colleagues providing affectionate care to residents—using humour and physical warmth while respecting residents’ dignity and personal preferences. However, when I asked Minnie what her job entailed, her response represented understandings shared by many RCAs, that is, that her primary duty was to care for the bodily needs of the resident population.

In a conversation with RCA Lena, she added insight into another aspect of the RCA job requirements. Lena spoke passionately about her experiences and what she considered to be her changing role in resident care in general, and care planning in particular. She stated,

Well, I’m a care aide. The role is devolving. At one point care aides used to be more involved in the care planning and the assessment of whether or not a care plan worked and that kind of thing and now, I don’t know whether it’s a function of collective bargaining or whatever, we no longer contribute as much. We more implement what we’re told to do. And so we, on a day-to-day basis we look at
what our residents’ need and try to meet those needs. But on a larger scale we largely implement what is or isn’t put in place by others.

Lena inferred that at one time in her career she experienced a feeling of empowerment in her role vis-à-vis decision-making and care planning, but this had passed. She alluded to her current role as one that had been downgraded to the daily execution of residents’ care plans that were put in place by others often at care conferences in which RCAs rarely participated: it was these meetings in which residents were discussed in light of their medical and psychosocial needs and histories. The cumulative impact was that direct carers’ felt less able to engage with residents at a relational level and did not feel like a valued part of the care team.

The intention was not to exclude carers. Rather, administrators talked about valuing care aide participation in care conferences and RCAs were generally aware of this. However, given their workload, carers themselves questioned the feasibility of their involvement. According to RCA Tom, the invitation to participate in a care conference was unrealistic in light of his workload. Tom stated, “as far as time goes, it’s almost impossible.” His co-workers also expressed the view that the demands of their workload prevented their involvement in care conferences, though they were expected to and did participate in the brief care meetings that were held on a daily basis. This perception appeared to produce a kind of oral culture in which carers shared their experiential knowledge of residents, as well as that attained through formal channels, with their peers by word of mouth.
Administrative Perspectives on Culture Change: “It’s not the what, but the how”

Data on organizational support for culture change was primarily generated through individual and group discussions, as well as PO sessions. In addition, a review of organizational documents provided insight into the formal structures and discourses that underpinned Cedar Grove’s process of culture change.

Led by the ED, the vision promoted by Cedar Grove included support for a shift in focus from task orientation (“what”) to more fluid care provision (“how”). In this change, the flexibility in the direct care team is key. Reflecting on the challenge of balancing job description with the goals of personalized care, an administrator notes:

Yes you’re (RCAs) responsible for bathing and mobility and feeding assistance and safety issues and any other thing that’s delegated by the nurse. That’s pretty well your job description. However, it’s not the “what” you do, it’s the “how” you do it. So if my job is to bathe and feed and say yes to whatever the nurse says, it’s nowhere written that I have to bathe Elizabeth on Tuesday at 2:00. I could be hanging out with Elizabeth and it can be really hot on a Wednesday and it’s kind of quiet and Elizabeth could be sweaty and cranky and I can say, “I feel like a bath, do you think that would just kind of make you feel better,” and if they say “yes,” and off we go and Elizabeth is feeling calm and it’s been a good thing and it’s when she wanted it. And then the next day we don’t bathe because you know you already did it and you’re into doing art or music or something. So it’s the

*how.*

In this scenario, under the supervision of nursing staff, the RCA is expected to consider the needs and desires of the resident over and above the requirements of the institution.
Rather than locating accomplishment in the completion of the task, administrators advocated or endorsed carers’ slowing down in order to achieve the goal of “being with” the resident. Here, it is the quality of the interaction and the degree to which it reflected the desires of the resident that is the preferred outcome of the care encounter, rather than the completion of the task itself.

**Achieving a Caring Culture: Promoting a Team Approach**

A key concept that was prevalent in the discourses of administration, one that was foundational to their promotion of culture change, was the differentiation between two types of organizational culture—one of entitlement versus one of achievement. During fieldwork, comparisons between these two types of culture were often raised in meetings and in interviews to highlight the rewards of the later vis-à-vis quality care. In an interview with an administrator, I asked her to explain the difference between the two:

So a culture of entitlement is, staff would see performance dialogues as bad. They would see feedback as bad. They would see management as very hierarchical and the enemy, for want of a better word. Tensions between union and management. Well, I’ve worked here for all these years. I deserve this. We’re family. We love each other. That to me is the culture of entitlement. Achievement is more, we’re a team, and a team is very different than family. But as a family, you allow for a dysfunction or you know, “oh Uncle Ned, he has been this way, it’s okay.” In a team it’s not okay. Everybody has to pitch in and help. We recognize and respect differences, but we all have a job to do and we all need to work together even if we’re different, it’s okay. You don’t allow someone to be dysfunctional or not take part, so we’re a team. Performance dialogues are an opportunity. Feedback is
a good thing. It’s about quality. It’s about measuring what we do. It’s about best practice, so that to me is a culture of achievement.

In another discussion, this administrator expanded on the notion of “family” and “business” highlighted above, stressing that the ultimate objective of culture change at Cedar Grove was teamwork:

We’re not family, nor do we want to be. We’re a team. We don’t want to love everybody because that’s not really… it’s a work environment. But we do want to give good care and we do want to be respectful, so I think the challenge is putting systems in place because we’re a business, although we’re non-profit, but still having systems that allow us to be spontaneous. So that this would be a place that I would want to live.

Thus, the creation of an interdisciplinary care “team” was an organizational goal. As members of this team, staff might be empowered to provide care in a milieu that nurtures and respects their skills and treats them as integral to the ability of the organization to fulfill its mission. Ultimately, the outcome of this process, as articulated above, would involve creating a residential setting that the carer might consider (as noted above), “a place that I would live in.”

The group meetings discussed earlier in this section represent one of the ways Cedar Grove administration endeavoured to generate a team of achievement that prioritized the “how” of care. Importantly, these facility-wide meetings demonstrated a commitment to culture change, entailing a substantial time and financial investment (namely, replacement direct-care labour costs) in fostering the facility’s social milieu. These meetings drew on principles of organizational change, the Eden Alternative, ACC
standards of care, as well as the DCM data generated in this study. Through these meetings administrators sought to facilitate carers’ commitment to the “team” in a forum where they could engage in an open and free dialogue about challenges staff faced in their respective roles. Led and organized by both a professional facilitator and key administrators, the objective of these meetings was to expand carers’ understanding of one another’s roles on the care team, and in so doing to engender respect for social needs and desires shared by residents and staff alike. Discussions focused on the practical skills associated with enabling carers to foster relationships with residents and to produce more meaningful work for themselves.

To this end, during meetings, care staff were guided in a brainstorming exercise to create individual staff initiatives that had the potential to improve the well-being of residents through increased and improved staff-resident social interactions. Specifically, participants were asked to identify a resident(s) in need of social contact and to develop an initiative geared toward engaging that elders(s) in unique and personal ways. These initiatives were expected to be brief (approximately 5-10 minutes) and to fit into carers’ daily job responsibilities. That is, in order to increase the likelihood of successful implementation, initiatives were not meant to be onerous, but rather fit into one’s normal schedule. Example of initiatives staff created included: a plan for RCA’s to provide hand rubs to residents of the SCU; a nurse engaging an isolated resident, on a regular basis, in a conversation on a topic they both shared an interest in; a food services staff proposed to involve a resident who loved helping in the delivery of food trays, and; a maintenance person identified a resident he knew to be lonely and incorporated a visiting initiative into his schedule. The ideas were diverse and engaging, reflecting the range of personalities
and skills of the carer, while also targeting identified social needs in residents. Staff initiatives were then shared on communication boards in the facility.

Although generally well received by carers, there was also evidence that some staff were resistant to the ideas generated in meetings. Disgruntled staff expressed feeling affronted by the suggestion of what they perceived as the inference that they needed to somehow “care more” or “care differently.” As one RCA stated, “I do it anyway, we all do.” In short, the view shared by some was that they already provided good care. Furthermore, they were opposed to the documentation of an initiative, stating that this formal requirement detracted from the spontaneity that characterized their current practice. There might also have been unspoken concern about changing workload requirements and possible disciplinary measures.

Despite resistance, administrators were committed to the plan and encouraged those opposed to commit to an initiative. It was apparent that administration wanted a deliverable from their investment in culture change. Therefore, this encouragement was formalized through the inclusion of staff initiatives in staff performance reviews (to be developed below). In this way, compliance with the new initiatives was enforced through organizational policy.

Administration also responded to group discussions that highlighted carers’ challenges around residents’ life histories. This included implementing two new organizational practices between the first and fourth group meeting that I attended. The first involved the creation of an orientation package for new residents and their families. A key part of the package was a document that elicited a photograph and a short paragraph of the resident’s biographical details. Family of the new resident were
encouraged to complete the document, ideally with the input of the resident, so that it
could be posted on the door of the new resident. Current residents were also involved in
this program. This biographical poster was designed to function as a type of memory-
box, used in many residential settings to alert staff to the details of the person behind the
“resident.” As RCA Tom suggested, exposure to biographical information served as a
foundation from which he could interact with a new resident to make her feel welcome.
Notably, this understanding of the tool suggested the value of its seamless integration in
practice, given that it did not necessitate computer use by RCAs, or other visitors. The
second change in practice involved the sharing of one resident’s biography per week at
care meetings held on Holly Street, with the intent that eventually, all care floors would
implement this practice and in turn, be more familiar with all residents’ life histories.

**Organizational Documents and the Language of Care**

Part of my immersion into the research site involved understanding what
discourses were at play in the culture. What I found was a diversity of terms in everyday
use and on various forms of documentation. A review of organizational documents
indicated significant ambiguity in key terminology. Documents produced by leadership
committees that both underpinned care practice and guided culture change revealed an
array of terms that were seemingly used interchangeably. For example, the term “client-
centred” was used in staff evaluation documents and Accreditation Canada also used
the term “client” when evaluating the organization on its’ ability to provide “Client-
Centred Services,” through its capacity to put “clients and families first” (ACC Report,
2010). Other documentation, such as the MDS/RAI system used “resident.” These
materials also used one of the following terms ‘client,” “elder,” or “resident” at different
times to address members of the resident population. However, the most prevalent term in everyday use in this culture was, overwhelmingly, “Elder.” This language was a vestige of Cedar Grove’s affiliation with the Eden Alternative, as was the term “neighbourhoods” in lieu of “floor” or “unit.” The sliding terms points to a structural or organizational confusion around notions central to person-centred care and to the way residents are seen and identified by members of the community.

Although Cedar Grove was unable to alter their physical structure to achieve smaller clusters of residents in keeping with the concept of “neighbourhood,” (McLean, 2007b, p. 243), they had implemented organizational and structural changes so that floor staff worked as a team, and more stable, permanent staffing was an organizational goal.

At no time during fieldwork did I hear a resident referred to with reference to his or her diagnosis, a negative practice that would fall under Kitwood’s Personal Detractor of labelling (University of Bradford, 2005, p. 72). As per DCM, to use a label as the foremost way to describe or relate to a resident serves to undermine his or her identity and moreover, is indicative of a care culture’s malignant social psychology (Kitwood, 1997). Interestingly, in my conversations with residents, there was ambivalence about the widely used idiom, “Elder.” For some, they felt that they were in fact “residents” of Cedar Grove and so preferred to be addressed as such; younger residents expressed feeling aged by the term, and others I spoke with liked the term because of its connotations with respect and wisdom.

As might be expected, organizational documents identified culture change as a priority. For example, Cedar Grove administration operationalized the goal of “being with” the resident through the formal evaluation structure of the “Employee Performance
Dialogue.” This internal document listed “Client-Centred Care” as a job-related competency. This competency was multifaceted and entailed that direct carers meet several practice-related expectations. Specifically, they were evaluated on their skills and caring in the following capacities: “Consciously adopts the client’s perspective about what matters;” “focuses on the person/relationship over and above the task;” “displays courtesy and sensitivity toward others;” “resolves difficult or emotional client situations;” “asks questions to understand client need;” “solicits feedback to improve care,” is “flexible in meeting client need;” and, “responds quickly and appropriately to request.” “Individual Staff Initiative” was another of the nine job-related competencies that staff were evaluated on. This competency appraised staff on the creation and implementation of the relationship-building initiative described earlier in this section. Through this evaluation of care practice, administrators’ endorsement of relationships between residents and staff in the care culture was formalized.

The drive toward care that created the conditions for increased and improved social connections between members of the Cedar Grove community was embedded in the Strategic Plan (2010-2013). This document listed “Resident/Family Satisfaction” as an operational goal. Within this goal, successful initiatives promoted care that was “person-centred.” In this light, initiatives had to consider the needs of family and residents, providing opportunities for choice and input while considering safety. Interestingly, a comparable goal was conspicuously absent from a similar document created in 1994, signifying perhaps the influence of the “personhood movement” that took off in the 1990’s (Innes, 2009). At that time, “resident care” was a relatively minor focus, compared to medical care, in the organization’s quest for quality improvement.
Both the Strategic Plan and the Performance Dialogue then, provide explicit expectation of relationships between staff and residents. In the former document, person-centred initiatives were more closely aligned with the Eden principles that required carers to address the “three plagues” of institutionalization; i.e., loneliness, boredom, and helplessness” (Thomas, 1996).

Interestingly, although documents revealed the promotion of aspects of person-centredness in policy and practice guidelines, the only verbal reference by residents, staff, or administrators to the term “person-centred” came through a response to a question from me that queried participants on its meaning. Because after several months of fieldwork I had not heard the phrase “person-centred care” applied in use, nor “personhood,” or any of the range of terms prevalent in dementia care literature, I began to overtly ask carers what relevance of the term “person-centred care” or its meaning in the context of their roles on the care team. Responses to this question varied widely. To some staff and administrators, this term described the care philosophy that they had always worked under. A direct carer shared this perspective in the following quote:

Well, as far as I’m concerned, I think I’ve always done person-centered care. How can you not look after somebody and not have it be person-centered care?

Because that’s why you’re here in the first place.

As this quote describes, there were staff that interpreted all LTRC as person-centred. Others considered the term “person-centred care” as a fad in LTRC, or as one staff member described it—“the flavour of the month.” To others, given the working conditions and the pressures of workloads, person-centred care was an impossible ideal, noting that, “there’s no way we’re person-centred.” Confusing the interpretation still
more, administrators considered person-centred care as in some ways passé, maintaining that they had “moved beyond” it and were forging ahead, as leaders in LTRC, with their own vision of culture change.

However, even though the language was not always clear and at times contradictory, and safety was an overarching organizational priority, my findings revealed an organizational commitment to a culture of care in which social relationships between all members of the community might flourish. In addition to on-going education and training, organizational structures were in place to guide and monitor carers on their capacity to personalize care and to foster relations with residents. These goals were formalized in organizational documents that grounded practice. These documents displayed a diversity of terminology to express their organizational goals in relation to culture change. Indeed, my ability to conduct this research at Cedar Grove might be understood as indicative of the organization’s openness and dedication to a care philosophy that surpassed traditional approaches to long-term residential care.

**Family Perspectives of Relational Care**

Data on family members’ experiences of care also pointed to a focus on relationships as a significant theme in the care culture. The data pointed to several main areas of significance to families\(^\text{11}\): 1) Family relations with their relative in care, 2) Family relationships with staff, and 3) Family opinions of relationships between their relative in care and the staff. As the vignettes in Chapter 5 demonstrate, residents enjoyed varying levels of familial support and interactions.

\(^{11}\) I use the terms “family” or “family members” in this study (as it was for the research site) to refer to a resident’s friend and/or family who is involved in the resident’s life and care at Cedar Grove.
Put another way, families varied in their participation at Cedar Grove. Some families were deeply involved, either in person or through regular correspondence with Cedar Grove through email and telephone calls. As expected, among family that I spoke with, the consensus was that a positive relationship with staff was vital to both their well-being and that of their relative. Notably, these family members maintained that their relative’s residency allowed them to once again enjoy a relationship with their loved one, given that many of the demands of day-to-day caring had been lifted.

An example of a family member’s view on relational care at Cedar Grove was introduced in the vignette on resident Emilia’s and her niece Freda. Freda was a highly involved family member who commented on her relations with staff and what they meant to her. On her rapport with staff, Freda resolutely stated: “I have a very good one!” Freda had frequent interactions with staff over the several years that her aunt lived at Cedar Grove. Generally, this aspect of her aunt’s care was something that she valued highly, and even when she had questions or complaints she maintained a deep respect for the work carers did. This respect made Freda hesitant to question carers or to complain, and she tended to focus mostly on experiences of positive communications with the direct care staff as well as with administrators. Overall, Freda considered care staff to be kind and considerate and she trusted them with the care of her beloved aunt. Importantly, she also felt that her aunt had a good relationship with staff.

Similarly, Barb—another family member—commended staff on their relationship with her mother Rachel, but also her mother’s relationship with care
staff: “Oh, they are so loving with her. She loves to hug and they are just really personable with her. But that’s what she puts out.” She was clear in her perception about the reciprocal nature of a caring relationship where staff responded to the needs of the mother for physical contact through hugs and affection, and in this way, the mother was able to convey her fondness for her carers. However, Barb also raised an aspect of relationship-in-care that troubled her. Evidently, Barb’s mother had become what Barb considered a “sounding board” for a few staff who would engage Rachel in stories of a personal nature. Barb felt that Rachel encouraged these relationships; at the same time, she shared with her daughter her concern for staff. Barb felt conflicted by this situation. On the one hand, she was grateful for her mother’s care and was happy that she interacted with staff; on the other hand, she felt that staff “crossed the line” when they burdened her mother with their personal troubles. This demonstrates the complexity of establishing relationships with boundaries that were comfortable/appropriate for both residents and staff.

While some residents did benefit from active and involved family members, most residents did not have a family member who was actively involved in their day-to-day life and care. During fieldwork, administration estimated that only about one-third of the resident population benefited from an involved family member. During this study, I attended six care conferences in which a total of 18 residents care plans were addressed. In only three cases did a family member participate in the care conference. Recalling RCA Lena’s comments on the vital advocacy role that family members play in the life of their
relative, this finding has profound implications for how care was enacted at Cedar Grove.

When I prodded, I learned that the reasons for the scarcity of family connection were numerous. For example, people cited demographic and socio-cultural changes that contributed to geographically dispersed families, dysfunctional families, small families, and residents with no families. In a conversation, Sally (leisure) commented:

These residents are in their 80’s and 90’s. The kids are on in years too. And you know, some live far away or, they’re coming to that age where they’re having medical issues as well, you know…. [Lists four women residents] didn’t have any kids.

An administrator echoed these observations:

And I think our world has changed. I think the children travel to lots more different places, have jobs in different places, and the ones that are here, I mean we do have some very involved families, and others you know it’s kind of, they’re not, it’s not that they don’t want to be here, they can’t be here. Their jobs are somewhere else.

Similarly, RCA Minnie noted:

Well a lot of them don’t have any children. A lot of the people, on [Holly Street] especially, don’t have any children. And the other thing is the ones that [Beeper goes off] do either have kids that are either still in school or whatnot themselves, and so, are the sandwich generation basically. They’ve got the parents and they’ve got the children well, they know we’re looking after their parents, so. Or there
have been disputes in families. The insight that family members were themselves aging and perhaps experiencing health concerns of their own is significant and points to a deep cultural or structural problems for LTRC in Canada. Furthermore, families might have experienced pressures associated with their working life and children, or perhaps their relationship with their elder was marked by conflict. Sally and Minnie referred to the fragmentation of families and the reality that many of the residents are without children of their own. All pointed to factors that served to decrease residents’ social networks of support.

Administration worked at connecting families with daily life at Cedar Grove in numerous ways. For instance, family members were encouraged to participate in the various committees that guide organizational policy and practice, such as “Quality and Risk Management,” and “Occupational Health and Safety.” According to one administrator, family involvement in the organizational decision-making was critical, “And that makes a huge difference. Those are outside fresh eyes and you can’t deny their interpretations.” Later she added, “If I had my way, I’d have family members on every committee we have.” Evidently, this stance was not shared by all, as some members of the staff worried about encountering misunderstandings and criticism from increased family involvement. In its early stages when I began this study, the use of social media (Facebook) represents another way the facility attempted to activate families. People were encouraged to “friend” Cedar Grove’s Facebook page, as a forum for exchanging news on the facility and individuals. This means to include families with geographical barriers to participation, as well as those nearby, represents a promising vehicle for inclusion in LTRC.
What had yet to be put into practice, though I was aware it was being considered, was the development of education and support for residents’ families, especially for those experiencing dementia. Direct carers identified this need and cited the presence of dementia as being detrimental to family involvement in care, and thus, consistent with findings from Adams & Gardiner (2005), may be negatively impacting the likelihood of triadic interactions i.e., the promotion of relations between residents, carers and families. RCA Lena elaborated on this gap in care in the following passage:

Yeah. It’s [family education/support] hugely important. But you know, I think there isn’t enough support. I’ve seen family come in for the first time and say, “Oh God, Grandma didn’t remember, she doesn’t know who I am.” So two conclusions, first of all I don’t matter to her anymore, or the fact that I’m here, she doesn’t know, yes or no. Someone needs to take her aside and say, your experience with your grandmother or your mother or whatever is going to be different, but for that moment she can be happy and you can be happy, whatever that looks like. The well adapted families know that, the ones that continue to visit know that it’s going to be, just because she can’t recall your name doesn’t mean there are no positive feelings there. But I feel like the families come, and they go “ahhh” and they might cry and they leave, they don’t come back and nobody reaches out, there isn’t that there.

Here, Lena identified a potential explanation for limited family participation in care, namely, fear and stigma, as well as a lack of understanding and knowledge about dementia and dementia care. Emotions of sadness, grief, and loss were also present. Moreover, she summed up what many staff had indicated to me in conversations; the
need for family-oriented education on dementia/dementia care, in particular, on how to have a successful visit with someone living with dementia. In this way, direct carers considered that some families might overcome their fear and discomfort, thus supporting their involvement in care.

Family member Freda supported the importance of this when she talked about the stereotypic beliefs on dementia that existed in her own family. According to Freda, Emilia’s extended family had an overwhelmingly negative view of her quality of life at Cedar Grove. Focused on what she could no longer do, these family members visited rarely. When they did, they would report to Freda that Emilia “didn’t know us at all.” Freda maintained that her family was generally of the opinion that residents “Are put there because they are useless.” This saddened and angered Freda, because in her opinion, although her aunt had communication and memory challenges, her constant contact with her aunt helped Freda appreciate Emilia in relation to her retained abilities in the present. In contrast to her family, to Freda, Emilia remained “full of beans and full of fun.”

The relative shortage of familial participation in the daily life of residents identified in this investigation points to a heightened need for residents to engage in relationships with carers and other residents. Whereas residents with family at Cedar Grove might have had some of their needs for social engagement met, at least in part, by family members, those without family lacked a critical resource. The shortage of active families in the lives of residents also points to another possible impediment to relational care—a lack of biographical information. Without the participation of family, the ability of carers to access residents’ life histories, particularly of those with dementia, was
compromised. This situation was the focus of initiatives in the facility that were in their beginning.

Chapter Summary

This chapter explored the data on the theme of relationship in the culture of care under investigation. Analysis of this data revealed the significance of relationship from the perspectives of members of facility that produce and reproduce the Cedar Grove culture. Residents expressed a longing for social connections with carers and identified workload and time pressures as barriers to conversations and social interactions. At least one resident presented her inability to engage with carers as a personal shortcoming; the result for this resident, Maria, was a lack of participation in her own care. DCM data from sessions on the SCU revealed that residents with dementia demonstrated their desire to communicate and engage in relationships with carers and other residents through a range of behaviours, both verbal and non-verbal. Moreover, this data also highlighted that the ability of carers to engage residents at a relational level contributed to their well-being.

Staff perspectives on relationships in care were elicited through group and individual discussions. Care practices that supported resident well-being were discussed by staff in relation to the organizational, structural issues that they considered to interfere with their ability to engage in relational care with residents. First among these was the introduction of RAI/MDS resident care planning, which produced a digital divide in the care culture. In addition to the challenges of computer access and literacy, there was also evidence of confusion around e-charts in relation to job requirements. As well, many
RCAs felt that workload and time pressures prevented their participation in care conferences, which further impeded their access to understandings of the resident in the context of their life history. Interactions and observations of staff revealed evidence of both an explicit and tacit awareness of a conflict between the expectations of administrators around culture change and day-to-day realities of their work.

Through PO sessions, interviews with administrators, and a review of policy documents, I found that the promotion of relationship surfaced as a vital component of the iteration of culture change I encountered at Cedar Grove. Administrators advanced a culture of achievement whereby the care team was empowered to focus not on the “what” of the job, but on the “how.” Goals for moving the organization forward were identifiable in policy documents, though there was a lack of common language used in the documents used to monitor and evaluate practice. Carers were evaluated, in part, on their ability to incorporate relational aspects of care into practice through a performance dialogue tool. In this way, administrators’ promotion of social connections in the care culture was supported through organizational policies. Moreover, data revealed how administrators demonstrated their flexibility through the implementation of practices that furthered their goals, while addressing the challenges identified by direct carers.

The final section of this chapter focused on the perspective of family members on relationship in care. Data revealed that family involvement ranged from people who were highly involved to virtual non-existence. As expected, those who were involved considered positive interactions with staff vital. However, data also exposed the fact that a majority of the resident population did not have a family member who was actively involved in their care. It also suggests that family members may be reluctant to critique or
raise concerns with staff due at least in part to their recognition of how overworked staff members were. Social and demographic factors such as geographically dispersed families were invoked to account for these circumstances. So too was the stigma of dementia and the need for dementia education as well as emotional support to encourage familial participation in the daily life of the facility when possible.
CHAPTER 8:
UNSTRUCTURED ACTIVITY AND SOCIAL ENGAGEMENT

The findings presented here attempt to move beyond the areas of structured activity and official programming well documented in the literature on leisure and therapeutic recreation in LTRC in order to shed light on how residents “pass time” when not “engaged in the official business of patient care,” as Gubrium’s landmark 1975 study of nursing home life puts it (1975/1997, p.158). This chapter presents empirical data on residents’ unstructured, everyday activity and social engagement at Cedar Grove. Listening to (and documenting) the stories shared by residents of their everyday/quotidian behaviours, habits, and routines—observing daily life in the care environment—I was able to access the ways in which they found meaning in their daily lives. I endeavour to offer a comprehensive picture of daily life for the people who lived at Cedar Grove.

This chapter begins with an exploration of the data on unstructured activity for Holly Street and Juniper Way residents, looking at their opinions on the topic as well as what they saw as detrimental to their activity levels. Findings on the importance of television to a group of residents on Juniper Way are developed, which then leads to an exploration of the social function of television as well as the data on residents’ connection to a particular genre of program, reality TV. Interestingly, television use emerged as a contentious issue at Cedar Grove, and I describe key findings on power relations between staff and administrators in relation to television. Next, I shift focus away from unstructured activities to explore a routine part of daily life in care,
specifically mealtimes and residents’ experiences of dining at Cedar Grove. Looking at the regular practices (rituals) around food and dining, I address the data on menu options, costs and subjective tastes. I also look at findings on the experience of dining and the potential for, and obstacles to, socialization. I then explore the use of food in celebrations at Cedar Grove. Data on the changing role of “leisure” at Cedar Grove, the meanings given to unstructured time and how everyday activity functions in social care on the SCU are then detailed. In the final section, I discuss social engagement and relational gestures between residents and between residents and staff that occurred on Holly Street, the SCU, during unstructured periods of their day.

**Resident Views on Activity and Social Engagement: Barriers to Participation**

Long-time residents often referred to what might be described as “the good old days” to describe a time in the past when Cedar Grove had a thriving, dynamic, leisure program that attracted numbers of people of varying functional and cognitive abilities from across the campus of care. Several of the bigger seasonal events that I attended had this capacity.

However, overall, staff and residents reported that attendance and individual engagement in structured activities was dwindling. Resident Hannah lamented what she perceived as a drop off in participation and a general reduction in the selection of activities offered: “People [in the past] were more sociable” and “there were more activities,” in Hannah’s opinion. She attributed the change to two factors: first the actions of the government, specifically, the cuts in funding for leisure staff — “it’s always a question of money” — and, second, the result of resident acuity (especially in relation to dementia and immobility). The result
was, as Hannah described it “that the atmosphere in the place has changed, so many people say that too. It’s not, it doesn’t seem to be sort of a care-free attitude.”

Hannah kept active by engaging in a mix of structured and unstructured activities, with the majority of her time spent engaged in the latter. The activities Hannah enjoyed most were the daily coffee times and the “pubs” held weekly in the main lounge. These events allowed her to enjoy a casual meeting and conversation with her friends, including visits with a friend from the assisted living portion of the campus of care who would read to her while they had tea. (Hannah could no longer see to read). These gatherings took place one floor down, in the main lounge, and Hannah looked forward to them.

Resident Maria was less than enthusiastic about the structured activities available. “I never get involved in anything,” she complained, and then added, “It’s an effort and I don’t want to be bothered with an effort.” This outlook meant that when Maria was not having her meals, most often, she spent time alone in her room, watching TV, listening to the radio, or sleeping. Like Hannah, Maria cited physical limitations as barriers to involvement in structured activities, and she experienced verbal challenges and pain that she said made her reluctant to join a large group. In Maria’s case, she blamed herself for her lack of connections at Cedar Grove. For Hannah, although she was better able to have her needs for activity met by attending activities she enjoyed, her decreasing mobility and vision meant that she was increasingly withdrawing from structured events. In both Maria’s and Hannah’s comments, there is evidence of a mismatch between
structured activities and the needs of the population. Others I spoke with in the community echoed this sentiment.

Residents also talked about their concern about the scheduling of events, and again the distance to where the activity took place complicated their attendance. A schedule was posted daily, and several times a day, activities were announced on an intercom system. At least, this was the practice when I began my site visits. However, in a move to reduce the institutional atmosphere of Cedar Grove, the intercom announcements were terminated during my fieldwork. Interestingly, while I found these announcements somewhat startling and generally inaudible, residents I spoke with missed them and a few residents mentioned that their cessation had a negative impact on their involvement in activity. One woman, with vision limitations, even circulated a petition to have the intercom announcements reinstated.

In a conversation with resident Anne, she talked about this change in organizational practice and the impact it had on her and on others:

Anne: Some of us find that very confusing because we can’t read the posters [activity schedule] and we ask people, and so many, there are so many newcomers and they don’t know what’s going on.

EK: Right. So you miss having those announcements?

Anne: Yes, um, I don’t know what the idea behind it is. It’s supposed to be make it, more like a family atmosphere. No interruptions. And you are supposed to rely on your memory on the special event that’s coming up.

EK: You miss them?
Anne: Yes. Well some of the staff try. They come to remind people. But they are busy of course.

In this way, the decision to discontinue the announcements was identified as a barrier to social engagement, despite its best intentions. Juniper Way residents identified a variety of these barriers to social engagement. In addition to the limitations imposed by the physical environment and distance between floors or areas, they suggested organizational practices around notification of events and location in which activities were held presented considerable barriers. The cumulative impact of these perceived barriers meant that a large and growing portion of the resident population spent much of their day, when not eating, on Juniper Way, close to their own rooms.

**Everyday Activity and “Reality TV”: Watching Television Together**

The television emerged as an important part of resident’s day-to-day activity. Many of the residents who spent much of their time on Juniper Way passed a good part of their day watching television. This meant that during my fieldwork, I spent considerable time observing a core group of residents, all women, watching TV. I was able to watch how they watched TV. The reason for residents’ presence in the TV area varied. One woman did not have a TV in her room, and in order to watch television needed to do so in the company of other residents. Some of the women chose not to join the scheduled activities offered on the main floor and gravitated toward the TV; others who required more care were regularly positioned in the TV area by staff. This helped with staff supervision while gesturing toward supporting socialization. Relative to other residents on this floor, the residents that were commonly found in the TV area tended to be the most functionally dependent on staff to meet their daily needs. It is important to
note that the TV was placed in a recessed area of the hall, a nook really, that was located adjacent to the Juniper Way nurses’ station (See Appendix A).

Through observation sessions and informal conversations with residents, I became increasingly interested in residents’ active engagement with television. I was surprised that they seemed to appreciate a particular genre of program commonly referred to as Reality TV. Together, the TV group and I watched *Hoarders: Buried Alive*, *Wife Swap*, *How Clean is Your House?*, and *Supernanny*. Reality TV tends to include shows that portray people in various everyday, domestic situations. Often, residents’ responded to negative depictions, such as badly behaved parents and children, such as those represented in the show *Supernanny*. Viewing this show or others like it, residents were motivated to vocalize their opinions, for example, on bad parenting or an untidy home.

During these sessions, I observed that not only did viewers engage with the characters on the screen, but they also used the opportunity to interact with each other. Viewing these so-called reality-based shows, people who were otherwise greatly challenged to communicate verbally would regularly call out or react to what they witnessed on the screen, as well as to one another. The frequency and content, both verbal and non-verbal, of these responses was markedly different than if they were watching, for example, an old movie or a situation comedy, with more fully developed, linear plot structures. As a person with a background in therapeutic programming for persons with dementia, I was struck by the quality and frequency of residents’ interactions with the TV and one another—both markers of good programming. I was also struck by the fact that these interactions were spontaneous and independent of the involvement of staff.
I was so impressed by what I had seen that I decided to augment my many hours of PO conducted on this floor with DCM. Using DCM, I was also able to map a core group of residents while they were watching television in this area. DCM data allowed me another tool with which to access how residents spent their time watching TV and, moreover, how TV watching might be connected to their well-being (or ill-being). In other words, DCM helped me to obtain further insight into residents’ experiences and the meaning of this activity in their everyday life.

The following are qualitative notes from a DCM session conducted in the sitting area on a Sunday, from 5:00-8:00 pm. For this session, I was seated in a chair that faced the residents gathered in a small group in front of screen:

4:50 pm – [Hoarders on TV] [Louise asleep in her reclining wheelchair at rear, appears comfortable]

5:00 pm – “Good heavens” [Agnes says twice to images of domestic chaos] “Oh my goodness” [Agnes to story of people being fined by the city] “Look at that now” “Oh imagine!” [Agnes says to RCA about story on TV, smiles and laughs]

[Maria en route to dinner, she is lined up against wall by RCA. She watches TV from her spot in the line-up]

5:27 pm – “Shhh, I can’t hear,” [Anne says to no one in particular, then] “Ohhh I love cats” [Agnes replies] “Ohhh that’s cute.”

6:58 – “The boy!” and “Ohhh my goodness” [Supernanny now on - Anne laughing at image of kids playing hockey on TV]
7:00 – [Agnes and Anne talk about show Wife Swap 7-8 pm. Both laugh as they exchange views on the two families]

“He’s so cute the way he lays there” [Agnes exclaims about the family dog, Anne replied, about the family] “The way they eat, like pigs! [Anne eyes transfixed on TV]

[Agnes wheeled away by RCA]

7:10 – “Even the dog is fed up” [Anne says about the family, and then comments on the dogs] “They’re so loving” and “Ohh look at the dog” [Anne responds to family on screen]

[RCA carries dirty diaper through sitting area. Agnes wheeled back.]

7:25 – [RN walks through]

[Laundry cart pushed by RCA rumbles along]

“Ohh look at the bird” [Agnes says while pointing to the screen and looking between screen and Anne]

[Pill smashing noise]

“Ohohhh gee their dog, he barked” [Anne about family dog]

During this session, data showed that Agnes and Anne were engaged in the behaviours of leisure (L) and articulation (A) for an extended period, and moreover that this behaviour had a positive impact on their well-being. According to DCM rules, for 71 % of the time she was mapped that Sunday evening, Anne was in a +1 state of mood and engagement, which increased to +3 (19%) and then +5 (10%).

The highest ME values were detected during resident-resident interactions. Data indicated that resident Anne’s mood and engagement, according to DCM guidelines, was
“very happy, cheerful mood” and “very absorbed” when she interacted with Agnes about the TV show. During this time, Agnes scored +1 for 85% of the time mapped and her ME score also rose to +3 for the remaining 15% when she interacted with Anne. For the other residents mapped during this period, two participants scored L+1 for the times they were awake and watching the TV, and the other scored C-1 (Cool, negative state of ill-being) for three time frames prior to an RCA removing her from the sitting area to go to bed. This data then showed that for some residents, their well-being, reflected in improved ME scores, was enhanced through this activity.

Supporting data was generated through PO. Residents’ ability to accrue benefits from viewing television in a group setting is captured in this field note from a PO session recorded on a Tuesday evening:

7:30 pm - The beverage/snack cart came by. Most took the milky-looking hot chocolate. I chatted with nurse. She is working the 3 - 11 pm shift, one of four in a row followed by several days off. She is looking forward to her break. Residents Anne, Margery, Mrs. N., and Agnes seated in their wheelchairs positioned in front of television. How Clean is your House?” is on. Margery’s eyes focus on screen and she nods off in turn. Anne stated emphatically, “Ooh some people are so dirty!” to scene of filthy bathroom. Mrs. N. laughs at a woman on screen who drops something while cleaning the kitchen. Margery joins in the laughter. Suzanna [from another floor] walks down the hall and joins the group. As she took her seat, she exclaimed, “I only watch it [the TV] when someone else is.” Reacting to the image of the piles of boxes in the bedroom, Anne exclaimed, “Some people are odd as hell.” Mrs. N. nods her head in agreement with Anne.
As these quotations illustrate, many of the group were actively engaged in TV viewing. Moreover, this activity had the potential to stimulate resident-resident interaction in ways that struck me as categorically different and more numerous than when these residents were watching an old movie or nature show. Again, these are residents who rarely left the floor to join structured activities offered by leisure staff.

These findings are perhaps not all that surprising given that television viewing might be seen to signify the continuation of a socio-cultural practice for residents. As noted earlier, Suzanna from assisted living, and others, came over to Juniper Way to watch TV with the group of regulars. Indeed, part of the process of my immersion in this culture came about through the time I spent in audience with this group. “Why don’t you sit down and watch the show with us,” Anne would say, inviting me to join them. The fact that watching television had been an activity, pastime, or behaviour in a resident’s life prior to moving to Cedar Grove emerged as significant. For example, new resident Ivy maintained that watching television in this common space was a way for her to feel “at home” and cared for at Cedar Grove. She spoke of her deep appreciation when “the girls” would tune the TV to her favourite morning show. In this way, Ivy was able to maintain her established daily routine in her new environment and develop a sense of belonging.

Barriers to resident engagement with the TV did emerge which included vision and hearing impairments, personal preferences in programming, and the location of the TV. For example, Augusta had poor vision and hearing and as a result rarely connected with the TV programs—or the other residents who were watching the TV. Hannah was a resident who preferred the news, so she watched TV by herself in her room. The location
of the television was also observed to impede optimal viewing. Its location next to the nurses’ station meant that the noise of the television and the business of care often conflicted, with a negative impact on (distracting) the residents who were watching television.

Another barrier to resident engagement related to cognitive abilities. Several of the residents who were regularly seated in the TV area lived with a dementia that was at a point where they were considerably challenged to engage with the TV or others in this space. These residents were often sleeping, looking at the screen only sporadically. For these people, this was a place to doze under the supervision of staff. Referencing this practice, various people—staff and family—expressed being troubled by the practice of congregating, or as a family member put it, “parking” residents in front of the television.

Television, Dementia Care, and Power: Who’s in Control of the Remote?

During my fieldwork, the issue of television within the theme of unstructured activity emerged as a point of debate and discord between staff and administrators. In other words, this aspect of LTRC that at first glance might seem inconsequential instead exposed aspects of the care culture in relation to hierarchy, power, and resistance. When I began fieldwork, there was a large flat-screen television in the common area of the SCU. This television was usually on between meals when there was no structured activity underway, and in the evening. In conversations with staff and administrators I learned that there had been a history of conflict around the use of the television in this multifunctional space. Issues such as noise levels, appropriate programming, and allegations of inappropriate use by staff were all points of contention. About four months into fieldwork, the SCU underwent renovations, after which the television was not
replaced. Instead, direct carers were encouraged to use the television next to the nurses’ station. This set did not have a cable connection, but it was a place where people could gather in the comfortable chairs and watch a DVD (typically a nature film or old movie) that was deemed appropriate. This shift meant that rather than being largely a backdrop to activity in the common area, direct carers were encouraged to use the television in the context of a discrete, purposeful activity in the smaller social area on the floor providing “quality” viewing program opportunities.

Many direct carers’ disagreed with this change in organizational policy. Overall, it was perceived as a unilateral decision handed down by administration. Some talked about how the ability to use the television helped to activate the common area in the periods between organized programs; this was especially the case on weekends. In a conversation with RCA Minnie, she lamented the changes, equating them with a move away from the promotion of “home” and respect for residents’ daily habits, to more of an institutional milieu. She stated:

It’s normal to hear dishes clanking. It’s normal to have conversation. Why does everything have to be so quiet and sterile? You know, to me it’s not a home…you have to have symphony music now and no television…they used to watch Coronation Street.

Also, carers talked about their use of the television to talk with residents about a favourite show or televised event, like the hockey game or a soap opera. In early PO sessions I observed this technique in use. For example, I saw resident Violet brighten considerably when a carer reminded her that the “Y and R” would soon be on TV. Staff wanted the television back. They felt television helped offset times of the day without leisure staff
coverage, and moreover, helped them meet the challenge of engaging SCU residents in any activity while still attending to the other things that their job required of them.12

For many carers, TV was a valued multipurpose resource that helped deal with shortage of staff and or finances for other activity. For administrators, the shift in policy around its use was presented as a vital element of culture change. In contrast to many carers’ views, administrators had decided that the television was detrimental to the type of social, therapeutic milieu that they sought to create. For them, the removal of the television from the dining area was important for noise reduction, and had produced other benefits for residents. Administrators maintained that following these modifications, some of the most agitated residents began to stay in their seats and finish their meal. One administrator referred to a time in the recent past when mealtimes had been “chaotic” and “Elders wouldn’t stay in their seats. They were always leaving. The TV was on…” For administration, weight gain for these individuals who had been distracted or agitated by television was quantifiable proof of the success of these practice changes. The TV did not return to the common area during my time in the field.

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**Food and the Dining Experience: Everyday Meals, Unstructured Activity, and Celebrations**

The other aspect of day-to-day life that emerged prominently, and perhaps unsurprisingly, related to meals and dining. Food played a pivotal role in daily life in this

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12 Indeed, leisure coverage on Holly Street was the responsibility of one leisure staff person (with some part-time support on weekends) working 6 hours per day, 5 days per week. In a typical day, multidisciplinary meetings like care conferences occupied a significant portion of a shift, as did charting and other assessment responsibilities. At that time, the staffing ratio of residents to RCAs was 7:1, with 35 residents per floor.
residential setting. As is the case outside the institution, the function of meals was multifaceted: food provided for individuals’ nutritional requirements, while offering residents opportunities for pleasure and socialization.

*Everyday Dining: Menu Options, Costs, and Subjective Taste*

Residents were provided with three meals plus two snacks per day. In addition, more snacks were available in between those times for those who wanted it. As noted earlier, residents of Juniper Way had to leave their floor to dine in the main lounge; given the size of the population served, this meant that two sittings per meal were offered to residents. Both floors had the same menu with individual dietary needs accommodated.

An example of a Cedar Grove menu:

<table>
<thead>
<tr>
<th>Breakfast Menu</th>
<th>Lunch Menu</th>
<th>Dinner Menu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eggs and toast (Choice of 2 styles of eggs)</td>
<td>Split pea soup - crackers/bread</td>
<td></td>
</tr>
<tr>
<td>Oatmeal porridge</td>
<td>Open-faced turkey sandwich with yam fries and gravy</td>
<td>Hawaiian pork with rice and spinach</td>
</tr>
<tr>
<td></td>
<td>Coleslaw</td>
<td>Couscous salad</td>
</tr>
<tr>
<td>Fruit yoghurt</td>
<td>Strawberries with crème</td>
<td>Fruit yoghurt</td>
</tr>
<tr>
<td></td>
<td>Alternate - cottage cheese</td>
<td>Alternate - Baked cod</td>
</tr>
<tr>
<td>Tea and coffee and juice</td>
<td>Tea and coffee and juice</td>
<td>Tea and coffee and juice</td>
</tr>
</tbody>
</table>
As these menus illustrate, dietary staff made the effort to offer residents food choices. This was done despite what might conservatively be called a tight budget. As a private, not-for-profit organization, 75% of costs associated with providing complex care to a Cedar Grove resident were covered through a direct grant from the local health authority while the remaining 25% came from residents’ fees. Within this cost structure, the facility had $5.75 to cover food (does not include staff costs) costs per resident per day. That meant that Cedar Grove provided food services to residents for $5.75, which then had to be divided by three meals a day, plus snacks. As a point of comparison, a study out of St. Michael’s Hospital in Ontario around the same time reported a daily allowance of $8.00 per patient per day on food and LTRC facilities in the province was reported at $7.33 (Retrieved September 10, 2011 from http://www.healthzone.ca/health/newsfeatures/research/article/1030362--hospitals-try-to-overcome-bad-food-reputation-by-going-local).

Although during PO sessions residents appeared to be generally happy with the menus and looked forward to meals, when I directly asked people what they thought about their meals, they gave a more critical summation of the quality of the food. For example, resident Maria shared her views on food in the following conversation:

EK: Are you a person who likes food? Did you cook much in your life?
Maria: I cooked at home, and for the family.
EK: Right. So is it that you think the food is bland, or there’s not enough, or [what else is lacking for you]?
Maria: It certainly is adequate amount… just not tasty.

Resident Ruth echoed this viewpoint, and stated, “And the food often isn’t good here.”
Similarly, resident Hannah found the menu generally bland and so she had voiced her concerns in a Resident Council Meeting. Hannah stated:

Well at the last meeting I suggested that, years ago we had, for Sunday morning breakfast, toast and a tea bun, which was nice replacing the usual toast. And Janet [food services director] said she’d look into it. And then I mentioned about the perogies. If they could bake or fry them they’d be more appetizing.

Hannah and others, though they were not always happy with the variety and taste of their meals, recognized that cost was a factor in both the variety and quality of the fare. As Maria summarized, “Yeah, they do the best they can.” This reflects my opinion as well: Although residents’ personal tastes and the food provided were often in variance, residents seemed to accept the menus. I felt that, given the costs of food and the budget dietary staff had to work with, the variety and quality of food available was remarkable.

The Dining Experience and Socialization

Day-to-day life at Cedar Grove was structured around meals. Residents were seated at square tables that accommodated four people per table. Exclusive of Holly Street, residents were given two possibilities of when they could have their meals, choosing either an early or late sitting. For instance, a resident who opted for an “early” sitting at lunch would eat at 12:00 pm and the “late” sitting was offered an hour later at 1:00 pm. Once a sitting was chosen by a resident, the option was generally fixed and was not altered on a daily basis. However, if someone was unwell, the resident was afforded the option to receive a food tray in his or her room. In my experience at Cedar Grove, residents rarely lingered over a meal. As noted in Chapter 7, the fact that people ate at different times meant that some of the opportunities that mealtimes might afford to
residents in terms of socialization were reduced. Recall resident Hannah who attributed the fact that she knew few of her neighbours to the fact that they ate at a different sitting. Also, although seating arrangements endeavoured to seat harmonious residents together, and some residents were observed to chat amongst themselves during meals, this was perhaps an exception rather than the norm. Residents’ mobility needs were also influential in seating arrangements during mealtimes. Given the restricted space of the dining room, the increasing number of people who required wheelchairs in the space was a challenge to accommodate.

Family member Barb commented on the physical and cognitive challenges that she felt limited resident interactions during meals.

Barb: And there were no conversations pretty well. I mean not very many conversations from my Mom’s table. I don’t know; you’ve been in there.

EK: Yeah.

Barb: I mean there is not a lot of talking.

EK: No, not across the table.

Barb: There is not a lot of that, but that’s because, I understand, as I saw changes with my Mom, she never initiated the last few years, she wouldn’t initiate. She was very good at answering questions and talking, loved to talk, but just you know, except if she was phoning me, she would never initiate a conversation.

Barb noted that her mother’s advancing dementia impacted her ability to engage those around her in conversation, though her mother would respond when approached by others.
Data on the experience of meals for Holly Street residents highlighted dining as a potential vehicle for socialization. For residents who were able to eat independently, meals were a chance to interact with staff and other residents. Care staff demonstrated a nuanced understanding of these residents’ food preferences, and they were cognizant of physical or cognitive limitations that might impact residents’ enjoyment of the meal. Often, carers spent time during meals encouraging residents to eat, accommodating them by altering seating situations, providing companionship, or offering food choices. The might also cut up food if needed and give a resident extra dessert if they desired it.

A significant portion of the resident population on Holly Street required assistance to eat. On this floor, because food was prepared downstairs in the main kitchen, hot food carts had been introduced at breakfast with the goal of expanding to the other meals. Because it allowed smells to permeate the space and to some extent create a more sociable or “homey” environment, the addition of the hot cart was seen to positively impact the dining on the SCU. For residents, dining provided people with more advanced dementia the opportunity to interact with staff in manner that was based not on medical, bodily care, at least three times per day. It was customary for these residents to be gathered together to dine at the same table, with the assistance of an RCA or nursing staff. Typically, one staff member helped two residents to eat.

Despite the potential for more positive interactions during meals, however, DCM data suggested that these interactions did not significantly impact the well-being of the residents during the time mapped. In general, DCM data showed that care interactions between staff and resident that occurred during a meal had no detectable impact on residents’ well-being, with residents scoring “F+1” (F – Food Behavioral Code Category
and +1, a neutral Mood and Engagement score) for most time frames observed. Accompanying qualitative notes revealed further insights into practice. There were instances of Personal Detractors (Ignoring) noted when staff spoke with one another “over” the resident that they assisted to eat. However, there was also evidence of Personal Enhancers (such as Comfort and Identity) recorded during the time frames when a carer helped a resident to eat while they interacted with them in a personalized, attentive way. Observational data also highlighted the length of times residents spent eating, which ranged from 15 – 25 minutes per meal on the SCU. It seemed that administrators’ practice goals of providing residents with a “dining experience” was compromised by the inherent challenges involved with both limited staff and the availability of staff that practiced personalized care while they assisted residents at mealtime.

**Celebrating with Food**

As is customary in many institutions, Cedar Grove used food and mealtimes for celebrations and structured events that were specifically designed to enhance social engagement. For example, at seasonal occasions and birthday parties, food trays were offered to supplement social gatherings. The following field notes describes the Christmas Party of 2011 held on Holly Street:

Margaret [administration] went around with a tray, offering people their choice of sausage rolls or meat triangles, while another staff handed out a choice of Christmas cake, short breads that were dyed pink, and tree-shaped cookies with bright green sprinkles. When it was his turn, Simon picked a triangle out and with his shaky hand ate it with a grin. To drink, there was a choice of eggnog, tea or coffee. Everyone nibbled away; most had the eggnog, while the pianist played
carols. Some people wore festive hats. A resident from Juniper Way, Estella came by and said that she hadn’t heard about the party, that she had just come down by accident and wasn’t dressed for the occasion. She proceeded to sing every song and took cookies back to her room for later.

Likewise, early on in fieldwork I attended one particularly memorable birthday party on Holly Street, a resident’s 100th. Led by leisure staff, many members of the direct care team got together to plan the special menu for the event. In preparation for the big day, residents had their hair done, the tables were set with tablecloths, and china cups, and an RCA who loved to bake made a gigantic chocolate cake. The cake was presented to the honoree in front of a cheering crowd of residents, staff, and visitors. Pictures were taken and snacks were offered to the celebrant and her visiting family as the pianist played some of her favourite music. This was an important event for the SCU and residents and staff used the opportunity to create social bonds that helped transform the quotidian life of the institution. The use of food during this event—and other special events as well—contributed to a festive atmosphere while allowing residents both choice and novelty in relation to food. Cakes, cookies, and savoury treats were always well received by residents and seemed to draw people to the social space, and keep them there.

Food Safety

The culture of safety developed in Chapter 6 was also found to impact how food was used in social events at Cedar Grove, and specifically, how food safety regulations dictated resident access to food. During fieldwork, a food licensing requirement was introduced that stipulated that no outside food could be brought into Cedar Grove and fed to residents. As an administrator explained to me,
Well, we’re liable. If you bring a birthday cake and you feed everybody on the floor and they get sick, it’s on our head…because we’ve got food licensing. They’re in there monitoring our kitchen. So if you make everybody sick…that’s the thing.

As this quote indicates, administration sought to prioritize interests and tastes while upholding safety. Recognizing the importance of food as a component in celebrations, administration encouraged staff to plan ahead and order cakes or other treats from dietary staff. This meant that all food served to residents was prepared on site. Staff was unhappy with this change. As with other practice changes that occurred close to or during fieldwork, data showed that direct carers felt powerless to oppose a policy they disagreed with. Staff expressed frustration over these restrictions, citing again a trend toward risk-aversion in the culture of care that negatively impacted residents’ freedoms and rights, in this case, to enjoy food produced outside the facility.

“Leisure” Reconsidered

Significant practice changes around how “leisure” was conceived and delivered proved to be another key component of culture change at Cedar Grove. As a part of the process of the organization’s quest to create a more meaningful existence for residents throughout their day, administrators led staff from across the care team in a reassessment of the current leisure program with the objective of creating a milieu in which the social needs of residents with dementia were a priority. In the conversations with the residents on Juniper Way and to a lesser extent, Holly Street residents, I noted a longing for activities they once enjoyed. Often, these desires were expressed in terms of activities they associated with “home”: listening to the radio, watching TV, chatting with friends
and family, having coffee, eating, reading the paper. Despite this culture’s exposure to the Eden Alternative, and continued reference to many of its 10 principles to further practice, leisure programming in the wider community was dominated by what has been described in the literature as “cruise ship” activities. Preplanned, generic, group activities characterize this type of conventional programming, where residents are invited to choose bingo, exercise, shuffleboard, bowling, trivia, current events, or arts and crafts. This approach to “leisure” appeared to conflict with a key administrator’s vision that prioritized social inclusion and the meaningful engagement of residents with dementia in their day-to-day life.

There were several reasons for this situation. I discovered that, as with RCA positions, leisure staff job descriptions conflicted in significant ways with expectations around culture change at Cedar Grove. Frontline leisure staff duties included, among other things, “carrying out activities such as bingo, crafts, games and sing-songs.” There was no emphasis on ways for staff to engage residents interpersonally, as they were involved in care or otherwise in less formal ways throughout the day. Practice was also influenced by the standardized charting system, the RAI/MDS that included an assessment of residents’ social engagement through activity. Done quarterly, and referenced in care conferences, this appraisal was completed by nursing staff and required their evaluation of the resident’s “ease interacting with others,” “ease doing structured activities,” “ease doing self initiated activities,” and whether the residents “establishes their own goals,” “pursues involvement in activities,” or “accepts invitations to group activity.” To these questions, staff could respond either “yes” or “no.”

Administrators’ vision of a culture change that entailed a flexible, fluid, and
interdisciplinary approach to social care, and which empowered staff to develop spontaneous social interactions, appeared to be missing from these organizational documents.

There was evidence of widespread recognition of residents’ changing needs and abilities in relation to social care. Carers understood that the reliance on structured activity (with staff facilitation and a group of residents) challenged people with dementia to participate and remain part of Cedar Grove’s social world. The utility and/or efficacy of providing generic, group activities which residents were expected to fit into more or less on their own volition was questioned. Indeed, as the staff initiatives detailed in Chapter 7 suggest, there was an expressed appreciation of informal opportunities for social engagement and connectivity with residents. More than this, at an organizational policy level, there was an objective to help foster or create social meaning in the lives of residents. The emphasis on less structured activity and more social care was most apparent on the SCU, which made sense, given that the majority of residents there lived with a moderate to advanced dementia. Here, although structured activities like music and horticulture therapy and current events groups continued to be offered, things had begun to change. It was apparent that staff recognized the need to create an environment capable of supporting people with dementia in unstructured activity, particularly in the many hours between regularly scheduled events.

Thus, one aspect of the culture change process that was evident involved a focus on enhancing residents’ ability to access unstructured, everyday activities. These efforts and attitudes were evident in conversations with leisure staff, and for example, in their desire to facilitate resident access to daily newspapers and visits to the hair salon. The
The importance of the latter, especially for the women of Holly Street cannot be overstated. This relatively insignificant aspect of “care” had significant rewards for the resident; not only did they benefit from time in the salon having her hair washed, coloured or set, but they also enjoyed the attention and complements they received from staff and others subsequent to the visit. As I observed on a number of occasions, these interactions were a great source of identity support and social engagement, vitally important in an environment where such opportunities were rare.

In a conversation with a direct carer, she talked about the challenge she faced creating opportunities for social engagement and meaningful activity. She described to me what a typical day looked like for a Holly Street resident:

So a usual day would be, just bringing in newspapers and sitting and visiting, and getting conversation going, and getting coffee klatch going, and that would be a usual day.

Involving residents in everyday activities like these had been identified as vital to creating a social milieu that evoked for residents feelings of domestic routine, or what they might consider “home.” Staff also involved residents in laundry folding and made use of the small kitchen that was located in a section of the common area to connect residents to food-related activity. In one conversation, a leisure staff commented on her use of food to engage residents at a sensory level:

You know people miss the smell of food. We need to be frying some onions, and frying some green tomatoes, or bacon. When I was frying some garlic or something, [resident] Violet said to me, “it smells like Mother’s here.”
Baking bread, frying food, or picking herbs from the flowerbeds, strategies that engaged residents at the sensory level, were implemented by direct carers to reduce the dehumanizing impact of living in “the institution.” Residents’ exposure to these everyday activities appeared to be entirely positive. For resident Violet, who could verbally express her feelings, the everyday stimulated positive memories for her; she said they took her back “home.”

The use of food in this space also permitted residents to tap into embodied domestic skills. These skills are linked to what DCM refers to as “Vocational” or work-like activities (University of Bradford, 2005). I comment on this behaviour in the following field note on Hilary, a woman with moderate dementia who was physically independent:

Hilary helped clean up after the party. She stacked and then re-stacked the dishwasher rack with the cups and saucers. She worked away at this for some time, clearly absorbed in this task, and appearing very content, more so than I had seen her before.

For Hilary, and others, the ability to perform domestic tasks they are skilled at provided rare opportunities for residents to draw on their abilities and to make positive contributions to the life of the facility.

*Residents-Resident Interactions in Unstructured Time: Relational Gestures on the SCU*

In earlier findings chapters the social connection between residents and carers is discussed. Here, I extend this discussion to look at observational data that highlighted resident-to-resident social interactions that occurred day-to-day at Cedar Grove.
absence of a structured activity, in the time “in-between” care and meals, residents engaged in the social world of Holly Street in diverse ways, including through social interactions with one another. This aspect of social life in the SCU was captured in the following field note:

Gerta takes a seat and proceeds to sing to herself, laughing and clapping her hands. Seated at a nearby table, Martha joins in, laughing and moving her hands in time with Gerta’s tune. Martha laughs easily and appears to welcome the activity. Violet walks over to the table and leans into Gerta, who stops singing to give Violet a sustained hug.

On another day, I observed Emilia, the most mobile member of her group, get up from her table and return with reading material she then shared with her seatmates, Ruth and Martha. In response, the two expressed their gratitude to Emilia.

Yet another example of this type of interaction was observed during a DCM session that involved residents Erma and Gaby. On that day, Erma, (a woman with moderate dementia who was physically able) was seated alone at a table with a large bouquet of flowers in front of her. For just over 10 minutes Erma interacted with the flowers, picking apart the petals of the various flowers in the vase. She then stood up, picked up the vase, and walked over to where resident Gaby was seated in her wheelchair. Together, Erma and Gaby interacted with one another; handling the flowers, each commented on how “lovely” they were, or words to that effect. They sustained this conversation for another two time frames, 10 minutes (Erma scored O+1, for the code Object, and A+3 – for Articulation, for this period). In this case, resident Erma had the physical ability and motivation to reach out and relate to another resident in this way.
Also, access to the flower vase facilitated this interaction. Gaby was a willing participant in the interface—she clearly welcomed the contact and both residents appeared buoyed by the exchange.

There were other findings of residents initiating caring behaviour to another resident or staff identified in the data. These behaviours varied, but often included one resident consoling another, offering to share food, or offering a hug to a fellow resident. However, the “recipient” did not always welcome these overtures. In situations where one resident demonstrated unwanted care for another resident, conflict often arose. An example of residents clashing in this way occurred during a DCM session:

Martha, a physically frail woman, told the woman seated next to her that she had to go to the bathroom. She sounded anxious and was frowning. Faith (a youngish, agile woman with frontotemporal dementia) heard this and got up to help Martha, and this annoyed Martha. Faith said, “I can help you sweetheart” and put her apron back on, much to Martha’s irritation. Martha snapped, “I don’t want this on, I’m hot enough!” Faith replied, “You have to dear” and then marched off. The apron was left on her. Martha was visibly shaken by the interaction. When the RCA came back to help her, Martha was full of praise for her, saying “Oh you’re wonderful, thank you so much,” as she was assisted to the washroom.

This encounter illustrates how Faith’s inclination to care for a fellow resident Martha was not welcomed, though her intentions were likely good. Martha, immobile and therefore unable to respond physically to Faith’s offer of assistance by removing herself from the situation, responded verbally. The presence of the
RCA prevented an escalation in this instance.

A frequent source of conflict on Holly Street often involved resident Gerta. Gerta had lost most of her ability to speak English, and because of this, her attempts to interact with other residents were often met with confusion and irritation. Adding to this, Gerta’s propensity to relate to other residents through physical affection—she greeted everyone with multiple kisses, regardless of the desires of the receiver—could also be off-putting and were often rebuffed or precipitated friction.

Caring gestures like those offered by Martha and Gerta were also extended by residents to staff. In addition to residents’ verbal acknowledgement of, and sympathy for, carers’ workloads, they expressed concern for staff by offering physical expressions of warmth. This concern was often expressed through a hug, a back or neck rub. In these exchanges, residents’ gestures toward staff often took on a parental quality. The age disparity between most of the resident population and the carers likely fostered this feeling of parental care and affection. An example of this type of care occurred between a resident from the SCU, a person who was often in pain and agitated, and an RCA. When the resident offered the RCA a neck rub, she accepted the resident’s invitation and the two sat together on a loveseat for several minutes for the exchange. This opportunity to reciprocate care had a noticeably positive impact on the resident’s mood, as well as that of the carer.

During fieldwork I observed many similar interactions between pairs of residents or between small groups that took place at times during the day that were unstructured by
formal activity. Such interactions are significant because they were spontaneous, largely unmediated by staff, and most often uplifting for those involved. Relational gestures of this nature were most often observed in residents with the ability to independently connect with others, that is, those with a moderate dementia who were either ambulatory or who used a wheelchair and were able to move it around unassisted.

**Chapter Summary**

With direct reference to my research question on the impact of a person-centred care philosophy on the daily life of residents, findings presented in this chapter highlight how residents spent their day and the aspects of the day in which they found meaning. Data revealed both what supported and what challenged their abilities to achieve a meaningful existence in this LTRC setting. Offering a comprehensive picture of daily life at Cedar Grove, these findings revealed that during the “in-between” or unstructured times of the day, residents engaged in a range of behaviours and spontaneous activities, many of which were relationally driven. Many of the residents on Juniper Way spoke of a desire to be active and connect with others, particularly through activities they associated with “home,” rather than those linked to structured leisure activities. Although many residents did participate in structured activity, a growing proportion of these residents either chose not to or was unable to leave the floor to interact with others in preplanned, group activities. Watching television was one of the ways that unstructured activity was carried out. Data explored in this chapter also exposed issues around food and dining: menu options, subjective tastes, supporting socialization over a meal, food safety, and the use of food to contribute to celebrations in the care culture.
Findings also revealed a shift in expectations around social care as a key part of the facility’s culture change process. Administrator’s vision for more balanced care involved a reconsideration of their “leisure” program toward a more flexible approach that focused on the social inclusion of residents with dementia. However, these goals were not yet fully integrated into the organizational structures that governed practice at Cedar Grove. Indication of the impact of this shift in emphasis was most evident on the SCU where leisure staff, in cooperation with administrators, employed a more fluid and accessible approach to social care of residents with dementia. Other data generated on the SCU revealed that residents with moderate/severe dementia, and who had the physical abilities to do so, initiated contact with others during unstructured periods of the day. Interactions between residents created positive, neutral, or negative outcomes, depending on the willingness of the other to participate in the encounter. Residents were observed to relate to staff in caring ways that were mutually beneficial.
CHAPTER 9:
DISCUSSION

This critical ethnography generated empirical data at Cedar Grove, an urban-based LTRC facility located in Western Canada that self-identified as undergoing culture change. The purpose of this study was to understand how a person-centred philosophy of care constructs daily life in a residential setting. To this end, I employed multiple ethnographic methods during a twelve-month period of fieldwork to obtain critical perspectives on the social and cultural practices of the care culture as well as on the meanings that culture members attached to them. I focused on how this cultural group functioned through its beliefs, language, behaviours, and rules (Creswell, 2007). In keeping with a critical, feminist epistemology, my fieldwork attempted to recognize and document issues of power, control, implicit and explicit agendas, and forms of resistance (Calasanti, 2004; Kincheloe & McLaren, 2005; Naples, 2003; Ray, 1996; Thomas, 1993). This focus extended to a reflexive analysis of my position in the field and the ethnographic gaze that I brought to this investigation (Coffey, 1999; Reed-Danahay, 2010). This study has an overtly political aim: to foreground issues of equality and social justice as they relate to people living and working in long term care. Through this critical methodology, I endeavoured to produce knowledge and discourse that might contribute to a larger understanding of policy and practice in the advance of LTRC in Canada.

This study’s findings extend understandings of what it is like to live and work in a LTRC facility that endeavours to put the “person” at the centre of care. The first of the findings chapters grounds this study in the day-to-day life of Cedar Grove to help frame
the complex issues that informed their experiences of culture change through the presentation of resident vignettes. In Chapter 6, I developed findings on the organization’s quest to balance a safety imperative with the needs of the person in care. Next, I described the significance of relationship in the lives of the people who live and work at Cedar Grove. Finally, Chapter 8 detailed the ways in which residents found meaning in everyday, unstructured activity as well as what challenged residents’ social engagement. In this discussion chapter, I develop these key findings in relation to the relevant literature, situating them in the context of a theoretical discussion.

Residents’ Social Worlds: An Intersectional Analysis

The resident vignettes developed in Chapter 5 were based on residents’ experiences of care and daily life and were designed to highlight the diversity of resident experiences in a facility that was undergoing culture change. In this section, I employ an intersectional lens to explore identity positions that emerged as significant in the lives of resident participants and to make connections between residents’ social locations and subjective experiences. Intersectionality, as an underpinning for critical research, helps to shed light on how various social categories intersect to create particular social locations for residents. The application of an intersectional perspective to this study’s findings helps to highlight how social structural factors construct one another (Krekula, 2009) and how these factors traverse to shape residents’ experiences of daily life, for better and for worse. Specifically, this lens has allowed me to consider the ways in which social categories like gender and economic status, mobility, cognitive status, and social capital via family participation in care produced particular experiences of being a resident at Cedar Grove. While there are only limited data to suggest the importance of gender and
socio-economic status, this study highlights the importance of mobility, cognitive impairment and family involvement as important resources that can serve to advantage or disadvantage residents. This study adds to the discourse on intersectionality by developing social categories and focusing on issues of power as they relate to aging and LTRC.

**Gender and Economic Factors.** Feminist scholars assert the centrality of gender in explorations of power relations and social life; this assertion is fundamental to my approach in LTRC. Characteristic of LTRC in Canada, the majority of Cedar Grove residents were older women. Because the vast majority of residents (and staff) are women, residential care remains a woman’s issue (Canadian Healthcare Association, 2009). The National Advisory Council on Aging (2005) has stated that gender has critical implications for residents’ access to economic capital. Older women are still more likely than older men to suffer economic vulnerability. Because they tend to live longer and earn lower incomes throughout their working life, older women are disadvantaged economically in this country. Widowhood, divorce and never being married also negatively impact older women’s economic status.

For many LTRC residents, old age represents the culmination of a lifetime of gender inequity and economic disparity. Although the province subsidizes LTRC facility fees, eligibility criteria and a means-testing method influence the amount of disposable income allowance a resident can retain for personal expenses (CUPE, 2009). This means that many low-income residents at Cedar Grove who received government subsidies for their facility fees had little left over to pay for things like clothing, meals out, or for
additional supports like physiotherapy. A 2010 study showed that in British Columbia, 63% of the long-term care residents were left with a personal allowance of $275.00 per month (Murphy, 2010). To put this amount into perspective, a haircut at Cedar Grove’s on-site salon cost around $30.00. A clear example of the difference financial resources made to the life of a resident was the ability of some to employ the services of a privately paid companion to meet their needs for socialization. This service offered support that exceeded what the facility could provide to residents but as was often apparent, this support was needed or might dramatically impact a resident’s well-being. The fact that this service was beyond the means of many in care suggests a significant inequality based on financial resources available. Specifically, this meant that some residents—i.e. those with the means to hire a private companion—were able to benefit from personalized care, and better realize the objectives of person-centred care.

In addition to gender, the resident profile was fairly uniform in terms of several social categories: age, ethnicity, language, and sexual orientation. In the following paragraphs, I will address the factors that did emerge in the data as significant and which intersected in ways that produced a diversity of experiences of the culture. These factors were identified as challenging to residents’ participation in the social world of Cedar Grove.

**Mobility and Cognitive Status.** Residents’ mobility significantly impacted the lives of the people who lived on Holly Street and Juniper Way. In conversations I had with direct carers and residents around the shift toward more complex care, the fact that most residents were increasingly unable to move independently or as I commonly heard, were
“in wheelchairs,” was raised at least as often as the fact that they were more likely to have numerous healthcare needs or to have dementia. Kitwood (1995/2007) addressed the unique needs of people with physical challenges in care situations in the following quote,

> For those who have forms of physical dependency which isolate (e.g. visual impairment), there is an especial need for help in maintaining contact with the social world. A person who is isolated from social contact is deprived of nourishment of their well-being. (p. 148)

The care interaction detailed in Chapter 7 that involved resident Violet and nurse Evelyn demonstrates how Violet’s mobility helped her obtain the engagement she sought from the nurse and also how that encounter had a positive outcome. In addition to interactions with staff, the ability to independently mobilize, with or without the use of a wheelchair, was shown to influence residents’ access to a number of areas of social life, such as contact with other residents, leisure activities, and the outside community. Also, importantly, ambulatory residents could remove themselves from the collective and obtain privacy if they so desired.

Observational data from the SCU showed that residents with the physical ability to initiate (verbal or non-verbal) social interactions with others were able to do so autonomously, while residents who were unable to physically execute this type of interaction were dependent on the awareness and discretion of staff to place them in a situations where they might chat with others, participate in an activity, or attain time alone. For some residents with dementia, the ability to walk (labeled “wandering”) enabled them to continue to participate in what might have been a lifelong pattern of behaviour that allowed them to cope with stressors. In essence then, residents—with or
without dementia—who had the ability to move around were literally in a better position to have their needs for engagement met. In other words, these findings reveal that mobility plays a key role in determining residents’ bodily experiences of daily life in the care culture. This is a vital perspective from which to understand not only experiences of dementia (Phinney & Chesla, 2003), but also how the care culture shaped an individual’s embodied selfhood (Kontos, 2004).

Residents’ mobility and cognitive status intersected. In general, residents of the SCU were more likely to have a dementia and be mobile. For the residents of Juniper Way who were generally more cognitively intact, those who were mobile were more likely to be able to independently access the wider community and the outside world, while those who were immobile spent more of their day on the floor. With or without cognitive impairment, immobile residents spent more time waiting, a common occurrence in LTRC (Liukkonen, 1995; Mitchell, Pilkington, Jonas-Simpson, Aiken, Carson, Fisher, Lyon, 2005). Given the facility’s physical design, at many times throughout the day, immobile residents sat queued in their wheelchairs waiting for the elevator to take them to (and return from) the main floor, where social events and meals were provided.

At times, residents’ physicality intersected with health and cognitive status to produce particular experiences of care for residents. For instance, the intersection of mobility and cognitive status were factors in placement within the facility and restraint use. Residents who were mobile and had dementia were considered most at risk for falls and “elopement,” resulting in a priority focus on the prevention of associated risks. This for example meant that they were more likely to be located in the SCU or have their mobility restricted in some way. Resident Emilia was an example of a mobile person with
dementia who would remove her security bracelet and leave the building and so was moved to the secure floor. Also, resident Violet was an example of a situation where a lap belt was used to address her perceived care needs. Immobile residents required staff to use mechanical supports, which influenced room allocation. Understandably, those residents who were receiving palliative or end-of-life were largely confined to their individual rooms.

This study’s exploration of the culture of care revealed the presence of dementia as a defining factor in the life of the resident. Despite attempts over the past twenty years to effect change in the social construction of the disease and change the discourses that surround it, the current construct of dementia remains predominantly negative. As noted by others, dementia remains inextricably linked to loss and dependency (Herskovits, 1995; McColgan, 2004). Within the facility, fears around the SCU revealed that Holly Street in particular occupied a stigmatized space that was set apart, marked (predominantly by other residents) with negative associations of isolation and limited freedoms. DCM data from the SCU revealed the extent to which residents relied on their social environment to have their psychological needs for comfort, identity, attachment, occupation and inclusion met. This is in keeping with Kitwood’s (1997) study of LTRC. Observation sessions conducted on weekends or evenings in the SCU suggested that residents were at a particular disadvantage during these periods. For example, residents in the common area had few interactions with staff during unstructured times, and signs of ill-being, such as repetitive behaviours, withdrawal and bodily tension were more frequently detected. Conversely, DCM data from the SCU showed residents’ well-being benefited from increased social engagement, in particular through personalized care
interactions. This finding supports other research that identifies interactions with carers as a main influence on residents’ well-being (Carpenter & Thompson, 2008; Custers, Kuin, Riksen-Walraven & Westerhof, 2011). Findings from this study suggest a need to better understand how physical mobility issues combine with dementia to impact residents’ well-being and risk for social exclusion.

**Family Participation as Social Capital.** The concept of social capital as benefits accrued to the individual through family and social networks (Portes, 1998) also helps elucidate residents’ diverse experiences at Cedar Grove. Although social capital is a contested and complex concept (Cattell, 2001), it is a useful perspective from which to view power inequalities between residents at Cedar Grove. Specifically, this study supports research that highlights the importance of family involvement as a pivotal individual resource, which correlates with positive outcomes and improved quality of life for residents (Gaugler, Zarit, & Pearlin 2003). Indeed, it is difficult to underestimate the influence of familial involvement in the day-to-day lives of the residents. Oppenheimer (2006) highlights how family and friends of people with dementia are “the most important safekeepers of their identities, insofar as they hold their histories, understand what is important to them in their former lives, and remember their preferences and habits” (p. 200). This is well understood, and biographical approaches in dementia care seek to draw on the expertise of families to contribute to, among other things, identity support for residents (Chaudhury, 2002b; Clarke, Hanson, & Ross, 2003). As other studies have identified (Boise & White, 2004; Reid, Chappell, & Gish, 2007; Utley-Smith, Colón-Emeric, Lekan-Rutledge, Ammarell, Bailey, Corazzini, Piven, & Anderson, 2009), my
findings suggest that although a significant portion of residents did not have involved family, for those who did, families were an important resource for communicating residents’ needs and preferences. One of the (potentially) key ways that their involvement made a difference in care provision is through their participation in care planning and care conferences. Family members were regularly (or as needed) invited to participate (in person, by phone or email) in meetings in which care plans were created and updated. This allowed family and friends to play a critical role in the decision-making, and effectively meant that their involvement could be vital to residents, especially those with dementia, requiring support to participate in key decisions that impact their lives (Hughes & Baldwin, 2006).

Although limited in numbers, the family members I spoke with who did participate in the care plans of their relatives commented on the important role they played in apprising carers of the health and well-being of their relative, making changes in care needs, and supporting their participation in the life of their relative. A few mentioned that their relative had attended, but did not actively participate in these discussions. Of the care conferences I attended during fieldwork, few included the participation of a family member and no residents were ever in attendance. Those I attended that did have a family present were markedly different than those without their participation. Namely, family involvement allowed for the exchange of narrative-based details of the resident’s life stories to supplement the largely clinical RAI/MDS-informed care plan content that dominated these meetings.

The importance of familial involvement in the life of the residents was also evident in less overt ways that went beyond taking part in care plan decision-making and
advocacy. For example, the presence, or not, of family in the life of the resident was also discernible through the level (high or low) of personalization displayed in individuals’ rooms. What might appear to be a relatively insignificant detail is not; a large body of research points to the significance of personal objects, photos, and memorabilia to convey vital biographical details about the person to others (Chaudhury, 2007a, 2007b; Habermas & Paha, 2002; Rubinstein, 2002; Sherman, 1995; Tobin, 1996; Whitmore, 2001). When carers view residents’ photographs, for example, they are able to obtain insight not only into the individual, but also to appreciate the wider social network of which the resident is a part (Kelson, 2006). By implication, when a resident has few personal items, they are disadvantaged in relation to this means of identity support.

For their part, staff recognized family involvement as essential to the well-being and quality of life of the resident, particularly for those with dementia. This was largely because families were seen to provide access to the needs and/or preferences of a resident who was challenged to communicate his or her needs without support. This is important but also has some worrisome implications: research has shown that family members and residents opinions are often divergent (Baldwin, 2008; Boise & White, 2004), and as McLean (2006) cautions, it is essential not to use information provided by families as the “‘valid’ external indicator of historical ‘truth’” (p. 167). Also, importantly, as Crespo and colleagues (2011) identified in their comparison of quality of life from the perspectives of residents, family and staff, residents rated their own quality of life higher than did their proxies. This highlights the importance of strategically involving families as contributors to culture change promoted by administration.
The majority of residents of Cedar Grove lacked the involvement of family and, therefore, had limited access to this valuable resource of social capital. It is significant in this study that many of the residents of the SCU were older, widowed or single women, who had dementia among other chronic conditions and who had little or no familial support to help them meet the daily challenges they faced. This finding reflects research on aging in post-industrial societies that suggests a trend toward geographically dispersed extended families and the related collapse of familial support systems: “spatial separation of generations” (Sibley, 2006, p. 173). What emerged in the data as a likely outcome of this trend was the need for direct carers to assume the role of “pseudo-family” for residents in order to advocate on their behalf. Ironically, this opinion was complicated by the point of view among many direct carers that their voices were not heard by the care team. The important point here is the importance of family for ensuring person-centred care, but also the role that carers could play as a substitute.

**Safety First: Space, Power, and Organizational Practices at Cedar Grove**

Compounding the complex intersectional dynamics discussed above, the second important macro-level concern highlighted by this study rests with an institutional safety imperative and the role this focus plays in shaping daily life in LTRC—often to the detriment of person-centred practice. The tension between safety and the quest to personalize care in LTRC is not new. As Kane (2001) suggests,

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13Shenk (2009) identified direct carers’ awareness of agency, their own and as a “force of agency” for residents as “moral agency” (p. 285). This researcher found that it was vital that direct carers experienced a sense of agency (over themselves and in their work) in order to find meaning in their work and to provide quality care.
Embedded in most of our rules and regulations is the idea that LTC should aspire to the best possible quality of life as is consistent with health and safety. But ordinary people may prefer the best health and safety outcomes possible that are consistent with a meaningful quality of life. (p. 296)

In light of the current resident profile and those projected for the near future, the significance of safety relative to the needs of the person is a key concern. Residential care settings like Cedar Grove have been referred to as “mini-hospitals” (HEU, 2009, p. 3). Indeed, Gubrium (1997) forecast a blurring of lines between residential and acute settings. In his introduction to a re-print of his seminal ethnography of Murray Manor (first published in 1975) Gubrium noted a major shift in care that reflects market forces and the influx from hospital whereby people are released into nursing homes “quicker and sicker” (p. xvi).

This study highlighted the increasing complexity of care required in LTRC, but it also reinforced an understanding that despite everything, this LTRC facility was not a hospital. People lived there, whether or not they considered it “home.” People also made it their working “home,” with the average length of employment exceeding 10 years and with more than a few RCAs and nurses who had worked there for almost 30 years. It was a vital, vibrant, and challenging space to be a part of during fieldwork. How then should the imperative for safety and person-centredness be understood?

**Balancing Risk and Freedom: Space, Power and Acts of Resistance**

An overarching “culture of safety” dramatically shaped the lives of individuals across all constituent groups—residents, staff, and family—of the research site—trumping individual needs or personal identities. This critical ethnography of life at Cedar
Grove, which I might term a “space of old age” (Sibley, 2006), revealed the ways in which issues of safety competed, conflicted, or were congruent with residents’ quality of life as well as staff roles and expectations. The imperative to ensure the physical safety of staff and residents is undeniably an expression of the society in which this long-term residential care facility operated; the facility was mandated to provide supportive care to older adults with complex needs while providing a safe working environment for staff. As was the case in many Canadian provinces at the time, residents of Cedar Grove displayed increased frailty and more medically complex psychosocial and health needs than has historically been the case in residential care settings. This shift toward more functionally dependent residents who are nearer to the end of life has transpired in “a world that is becoming more risk-averse and more litigious” (Dewing, 2006, p. 245). It has also occurred in a climate of limited and dwindling financial resources where there is marginal representation for long-term care issues on national health care agendas. Aspects of this shift in LTRC and organizational awareness of liability and economic issues in relation to residents’ safety was apparent at Cedar Grove. Indeed, even the shift away from formal affiliation with the more humanistic philosophies of the Eden Alternative toward Accreditation Canada is evidence of the care facility’s commitment to the provision of a safe environment for residents and staff that also entailed cost savings (affiliation fees) for the organization.

Foucault and Goffman both offer insight into how the safety imperative might be seen to shape the lives of members of the care culture. Their respective analyses of how societies organize people help to elucidate and contextualize many of the organizational practices that shaped the social spaces of Cedar Grove. For example, Foucault’s work on
disciplinary mechanisms and the connections between space and power as characteristics of features of the institution is vital to interpretation of the various practices I observed being carried out in the name of safety or risk management. In my fieldwork, I witnessed how every aspect of residents’ lives was managed through what Foucault (1999) references as spatial partitioning and social control (p. 44).

The legacies of Bentham’s architectural figure of Panopticism (Foucault, 1980, 1963/2003) and the associated gaze, produced daily life for residents and staff, as was evident around mealtimes and with the use of the common area in the SCU. In fact, it could be argued that the most obvious impact of the safety discourse/practice could be seen through the use of space in the facility. Constructed in the 1980s, Cedar Grove’s physical structure was inextricably linked to organizational practices of surveillance and segregation. Residents and carers lived and worked in a built environment that replicated an acute care hospital with rooms on both sides of T-shaped corridors, nursing stations and sporadic social areas on each of the care floors. The physical design of Cedar Grove did not reflect the needs of its current resident population and presented challenges related to privacy and autonomy. This challenge is not unique to this facility: as Torrington (2007) indicates, a major issue in the design of residential settings is creating environments that provide safety and security while supporting freedom of movement.

Ironically, this building’s physical design made it difficult to ensure the safety of its resident population because of the numerous divided rooms, reminiscent of Goffman’s (1961/1991) “environmental barriers” to social inclusion that mark institutional settings. Therefore, in order to maximize the potential for residents’ physical safety, people were encouraged to spend much of their time outside their private rooms in common areas.
these open spaces, people ate, recreated, and generally spent most of their time under the watchful gaze of staff (and in some cases, private companions). In this schema, residents of the SCU were most visible and had least access to privacy resulting in monitoring and surveillance techniques that helped keep residents safe functioned through what Foucault, (1977/1995) described as a production of a “state of conscious and permanent visibility” (p. 201).

These Panoptic practices are also in keeping with Goffman’s (1961/1991) presentation of the central feature of an (total) institution, which he described as characterized by the breakdown in barriers between the three spheres of social life. Goffman points out that although a basic arrangement of modern societies is the separation of the places people eat, sleep, work, and play, institutional life is markedly different. Rather, institutionalization dictates that all aspects of life are conducted, firstly, in “the same place and under the same authority,” secondly, that activity is “carried on in the immediate company of a large batch of others,” and thirdly, that there is “a tight scheduling of activities” (Goffman, 1961/1991, p.17). With staffing levels insufficient to meet the increasingly complex needs of residents (a perception that was prevalent in discussions with staff, residents and family members), Cedar Grove did in fact tend toward increased uses of space in ways that mirror Goffman’s description of institutional life. Renovations and programming decisions helped to maximize the practical and economic use of common areas. Also, recent changes in care practice enabled the facility to maximize safety efforts with fewer staff by physically positioning the majority of residents in one area for most of the day where carers were better able to ensure the physical well-being of a greater number of residents.
At its most basic level, a Panopticon is designed to promote efficiencies and save cost: this “system of surveillance…involves very little expense. There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze…” (Foucault, 1980, p. 155). Here, the various costs (staffing and material resources) associated with residential care influencing practice supports McLean’s (2007b) contention that of the many functions the “nursing home” serves in society, it is principally, a business where finances are always at the forefront of decisions made at the organizational level. Given the current economic climate and the dominant discourses around LTRC fiscal restraints, the function of the gaze as a cost saving mechanism—one that coincides with the safety imperative—represents an important perspective from which to interpret care interactions and organizational policy. The pervasiveness of the gaze then highlights an important point in the consideration of culture change in LTRC. As there was in Bentham’s time, there are still significant pressures on administrators and staff to find ways of maintaining cost effective practices. A key facet of this study is framed in relation to the economic aspect of a care provision and its potential conflict with tenets of person-centred care.

Findings also suggest that the imposition of these practices created a type of hierarchy based on residents’ social power in the facility, which led to the marginalization of some residents relative to others. Namely, the degree of stigma attached to the various levels of care at Cedar Grove appears to be directly proportional to the level of monitoring and surveillance the resident lived under—the more at risk an individual was deemed to be, the more visible she was. At the top of the hierarchy was Independent Living, where residents were perceived as self-governing and able to enjoy
freedoms associated with autonomy and citizenship. The next rung down the hierarchy ladder was Assisted Living; Juniper Way and the other complex care floors followed this. These residents were in-between the status of independence and restriction. At the bottom of the hierarchy was Holly Street, the SCU. Those evaluated to be most “at risk” tend to receive care in the SCU. Here, I learned through conversations with individuals from across Cedar Grove’s care culture, that Holly Street functioned as what Foucault calls a heterotopia—a space of otherness—where people whose behaviours are considered outside a dominant norm reside (Foucault, 1967/1984).

My findings around spatial use are supported by Gilbert’s (2006) research that developed Foucault’s notion of governmentality to explore health and aging. Gilbert highlighted the social practice of segregation in society that is based on older people’s ability to self-manage. Gilbert (2006) stated,

Actions of ‘self-managing’ individuals are deemed to be rational, their choices authoritative and consistent with the idea of an autonomous citizen. In contrast, those who fail to self-manage are considered irrational and their actions risky, individuals or in some instances whole sections of the population experience quite different forms of governance and surveillance. (p. 75)

This insight sheds light on many of the practices used at Cedar Grove to care for residents, in particular, those with moderate to advanced dementia whose ability to self-direct their day-to-day was severely compromised. The evaluation, monitoring, and prevention of actions that might be considered “risky” were vital components of care culture because they helped fulfill the organization’s directive to keep residents “safe.” Specifically, policy and practices were designed to reduce the potential for physical harm.
to residents, such as that incurred through falls and wandering behaviour. By increasing residents’ visibility, carers could better exert power and control in the quest to prevent falls. Falls in LTRC are also considered an outcome of “wandering,” another widely researched dementia-related behaviour that is most often constructed as a “problem” rather than a “natural activity” (Dewing, 2006). Residents who were likely to “elope” were either placed on the secure floor or fitted with security bracelets. Following several safety breaches, a policy was enacted that stipulated if a resident was to leave the secure unit, they had to be accompanied by a staff member (or family). Thus, the ability to hire a privately paid companion enabled some residents to resist an institutionalized process of othering by maintaining a modicum of power through his or her continued access to the wider community, outside the institution and beyond the direct gaze of carers.

Challenging Foucault’s depiction of the ubiquity of disciplinary mechanisms in institutional care was empirical data on the various acts of resistance enacted by residents. Indeed, Foucault has been critiqued for his bleak depiction of individuals as “docile bodies” who lack agency and are at the mercy of a disinterested all-powerful government (Grenier & Leonard, 2006; Sibley, 2006). McColgan (2005) found that residents exhibited power in their day-to-day life by independently choosing a place to sit. At Cedar Grove, whether it was refusing care, calling out, leaving a room or the building, or the myriad daily occurrences I observed whereby residents did not go along with decisions made for them by others, residents demonstrated active resistance. Stan’s story (detailed on page 175) revealed an extreme example of resistance when he eluded restrictions imposed on him by virtue of his position as a resident of the SCU when he
learned the security codes that enabled him to leave the building, and then return of his own volition.

This study lends texture to the tension between safety and person-centeredness. It highlights how complicated this practice of balancing resident risks and freedoms actually is. The process of decision-making that the organization employed to determine residents’ relative risk was multifaceted. Liability issues and costs of care came into play to confound residents’ needs and wishes. Whether a person was deemed at risk for falls, or considered to benefit from a private companion, or the need for physical or “chemical” restraint was in question, none of these decisions were straightforward. Adding to this was residents’ lack of passivity—there were examples of resistance whereby individuals attempted to exercise their autonomy by making choices in their daily lives that challenged carers to execute the mandate of resident safety.

Making Decisions: Establishing Best Interests and Gaps in Practice

Although one’s ability to make one’s own decisions is fundamental to Western society, this basic ideal is complicated by the presence of dementia, particularly in an institutional setting. During fieldwork, I saw that important clinical care decisions were integral to life at Cedar Grove. It became evident that for many residents, the ability to make autonomous decisions had an enormous influence on their lives, but these decisions were often impacted by dementia. I would add that people generally seek the advice of those who care about them when making important healthcare and life decisions. At times, the opinions of the various constituent groups in the care culture differed regarding care decisions, such as was the case with resident Violet and the decision to use (least) restraints to keep her “safe.” At the organizational level, judgments hinged on safety, and
as with other issues, were made within the framework of the evaluations of professional
carers where residents’ behaviours and abilities were assessed in relation to an objective
“norm.” Yet, there was also a less clinical or interpersonal appraisal at play. Namely,
these decisions appeared to be rooted in the relationships that existed between the parties
involved, as opposed to the application of an impersonal regulation or edict. In practice,
although regulatory policies were considered and safety was always the bottom line, there
was also evidence of a more person-centred approach to clinical decision-making. The
Cedar Grove staff and administrators endeavoured to consider the implications and
meaning to the resident if the person, for example, were to be moved to the secure floor
or the use of restraints was in question. Knowing and caring for the residents as people,
these decisions were often imbued with “anguist” as one administrator expressed.
The practice of decision making was described in the stories of residents Stan, Emilia,
and Ruth (detailed in Chapter 6) through which we learned how the organization engaged
in a lengthy negotiation process that went beyond a biomedical understanding to an
ethical one. Hughes and Baldwin’s (2006) statement that “there is almost no decision that
we make in dementia care that does not involve a question of right or wrong” (p. 31)
lends support to this finding. The Cedar Grove care team struggled to make ethical
decisions by acting on empathetic understandings of the needs/preferences of the person
(as staff understood these), and though this proved challenging, they sought the input of
the individual and their family member whenever possible. This type of inclusive
decision-making, which rested on a variety of perspectives, sought to establish what has
been described in the literature as acting in the best interests of the person with dementia
(Hughes & Baldwin, 2006; Martin, 2009; Tuckett, 2005).
Where Cedar Grove struggled was in their ability to involve residents in “everyday” decisions. In interviews, residents talked about their perception of a lack of involvement in seemingly mundane aspects of their day. Examples they gave included, choosing what to wear, what to watch on TV, when to have coffee, or when or what to eat. An illustration of this gap emerged during an interview with a family member who shared her dissatisfaction with staff completing tasks, like cutting up food, when her aunt was still capable of doing this task independently. She feared that this practice would lead to lost abilities. This niece had a point. In effect, when a carer does for a resident what they are able to do for themselves, they are excluding the resident from everyday decisions and practices. Adding critical insight into this tendency, a direct carer remarked that it often takes longer to facilitate a resident to complete a task than it does to do it for them. Persson and Wästerfors (2008) link the idea of doing for a resident what they could do themselves to staff perception of a lack of time and other resources. Regardless, doing for oneself is a key element of autonomy and crucial to well-being.

Harnett (2010) points out that qualitative research highlights the fact that although policy makers and administrators may deem everyday matters “trivial,” they may in fact be very important to the resident (p. 292). Edvardsson, Fetherstonhaugh & Nay (2010) found that opportunities to make these types of decisions were fundamental to participants’ perceptions of “good care, i.e. person-centred care,” and helped them to continue to live as “normal” a life as possible (p. 2614). Similarly, Tuckett (2007) maintains that the ability and opportunity to exercise one’s autonomy is vital to residents’ physical and psychological health and is a critical component of quality of life that is routinely challenged in long-term care. However, as Manthorpe (2004) contends, there is
a tendency for the perception of high risk to eclipse residents’ citizenship rights and personal preferences, such as those linked to care planning and implementation.

When resident Maria described her morning care, she illustrated a routinely missed opportunity for staff to capitalize on occupation by engaging her “decisional autonomy” (Boyle, 2008) in everyday matters. When she declared, “Well they dress you… I let them do it I don’t know, I never questioned it, so I just let them do it,” she highlighted how a resident can be excluded from making even the most basic decisions in her day, an interaction that would hardly have cost the carer undue time or effort. This quote also suggests a possible means toward the creation of “home,” that is, the prioritization in care of residents’ inclusion in these types of everyday life decisions and processes. At home, we make decisions about what we wear and whether or not to have coffee, eat breakfast in our pajamas, or what to listen to on the radio or television.

Observational data on care interactions from this study revealed times when residents of Cedar Grove might have been (but were not) approached in a collaborative manner around a seemingly small decision, pointing to a key area for future focus and development. Reflecting on these exclusionary practices around everyday decision-making—around decisions that people living outside an institution make countless times a day and are able to take for granted—it seemed to me that valuable opportunities were being missed. Administration promoted the importance of providing opportunities for residents to either act autonomously or for staff to facilitate residents’ everyday decision-making and collaboration in care. Despite these good intentions, the organizational imperative to maintain safety/mitigate risk tended to define every day life in the facility. Little research has explored this area of apparent conflict between philosophical approach
and material realities in any depth. This study suggests the need to explore further what
decisions persons with dementia can and should make in light of the importance of better
understanding the organizational constraints that necessarily limit resident decision-

Challenges to Relational Care Practice

There are four key relationship-focused challenges that, in combination, hindered
the process of culture change underway at Cedar Grove: 1) Time Constraints, Workload,
and Resident Acuity, 2) Staff Hierarchy and Lateral Power, 3) Finding the Right
Message: “Serving Tea” as “Actual Work,” and, 4) The Use of Resident Biography in
Practice. It is important to note that the safety imperative underpins these challenges,
impacting residents and staff in significant and diverse ways.

1) Workload, Resident Acuity, and Job Descriptions

This study revealed that a nexus of time constraints, workload and increased
numbers of residents with greater care needs (what is referred to in LTRC as higher
resident acuity levels) presents important challenges to the culture change objectives
articulated by the organization. Understaffing in long-term care is epidemic (Banerjee et
al., 2008) and constitutes a significant hurdle in dementia care, because as research
identifies, there is a positive relationship between adequate staffing levels and better care
(Collier & Harrington, 2008; HEU, 2009; Kayser-Jones, 2003; Lopez, 2006a; McGregor
et al., 2006; Murphy, 2006; Schnelle et al., 2004; Zhang & Grabowski, 2004). When
RCA Sam shared “there’s no time for kind, calm caring,” she spoke for many of her co-
workers who, although they recognized the culture change envisioned by administration,
still felt that the demands of the job rendered them powerless to implement changes in practice. In short, it was difficult for direct carers to focus on the “how” of care when they were overwhelmed by responsibilities associated with the “what.”

Findings from my study suggest that this apparent impasse may largely be attributed as an outcome of two interrelated aspects of resident acuity: residents’ increased physical dependency and increased numbers of residents with dementia. One result of this impasse seems to be staff perception of personal injury as an inevitable part of their job. There was a prevalent belief that when you care for sick older people, especially those with dementia, you will get hurt. This association is supported in research; a recent study on musculoskeletal injuries (MSIs) among health care workers found that in B.C., the sector had a higher rate of injury than all other industries. Moreover, RCAs were one of two occupations (the other being facility support service workers) with the highest relative risks for, and incidence of, MSIs in the field (Ngan, Drebit, Siow, Yu, Keen & Alamgir, 2010). A report by WorkSafeBC (2003) identified physical workload as “intense” across facilities sites, particularly before breakfast when “residents are wakened, transferred, dressed, and toileted” (p. 3). Injury was due less to repositioning or transferring residents from one place to another, and more to do with helping them with activities of daily living like dressing and washing.

The second significant aspect of the time constraint, workload and resident acuity nexus relates to behavioural challenges associated with dementia. Observations and conversations with staff revealed how many linked aggression with dementia. The issue of resident aggression in long-term care has been the focus of numerous studies of worker safety in the province (Boyd, Malm, Mitchell, 2004; Cohen et al., 2003; Workers’
Compensation Board, 2006). Adding to this, as Banerjee and colleagues (2008) explain, violence in LTRC highlights this intersection of gender and labour issues. Given the gendered nature of care work, violence in LTRC is a women’s issue, and increasingly, an issue for women from racialized and/or immigrant groups. However, as these researchers suggest, this type of gender analysis is largely absent in the LTRC literature.

Cedar Grove’s cultural change was based on pro-actively recognizing dementia-related violence as an important obstacle to the culture of safety the institution sought to develop. And it was engaged in a process of identifying triggers and preventing dementia-related aggression. Consistent with a person-centred approach, Cedar Grove’s responses to the problem reflected an appreciation of aggression not solely as a product of brain deterioration, but rather, a resident’s desire to communicate his or her “unmet needs” (Chenoweth et al., 2009; Hancock et al., 2006; Kovach et al., 2005; Cohen-Mansfield et al., 2007). Organizational practices reflected an understanding of dementia behaviours as social or relational and a desire to construct a dementia-appropriate care setting similar to that described in research by Day, Carreon, & Stump (2000), Diaz Moore (2004), and Morgan & Stewart (1997). Discussing residents’ unmet needs in care meetings, staff considered aspects of care practice, the facility environment, or personal factors (i.e. background or personality) that might contribute to problematic behaviours. Often these needs were talked about as an expression of pain and/or fear. To understand root causes of present day behaviours, residents’ life histories were also discussed. Despite these encouraging attitudes and related practices, more needs to be done.

Administration formulated several strategies focused on reducing the conditions for resident aggression toward staff and other residents. The practice of aligning a
resident with a favourite staff and utilizing stickers on doors to serve as a visual reminder of a resident’s potential for aggression. Despite the goal of these and other strategies to create a safer work and living environment, staff still saw violence as an expected part of care work. Again, this reflected findings identified by Banerjee and colleagues (2008), who compared rates of violence and working conditions in Canadian (Manitoba, Ontario and Nova Scotia) and Nordic countries (Denmark, Finland, Norway, and Sweden), especially their “deeply troubling” finding that personal support workers (in B.C., equivalent to RCA) saw violence as “a constant and ongoing part of working in Canadian facilities” (Banerjee et al., 2008, p. iv)—more so than did their Nordic counterparts.

Through my study, I came to understand that the apparent impasse between organizational goals and staff perceptions was a consequence of a lack of flexibility in staff roles and job descriptions. Like Brodaty, Draper and Low (2003), I found that staff who work with residents with dementia, particularly on the day shift, experienced high levels of stress. Similarly, McCormack and colleagues (2010) cite workload as the primary cause of stress among nurses. Although social care was included in the RCA list of roles and responsibilities, it was literally down the list; at the time of fieldwork, social care had not fully entered the cultural practices and discourse of the direct care team. This finding highlights (Cohen-Mansfield & Bester, 2006) contention that flexibility needs to be a key element of person-centred care.

2) Staff Hierarchy and Lateral Power

Findings from this study demonstrate how power relations among RCAs represent a significant challenge to the organization’s desire to foreground social care. Data show that lateral power relations framed the autonomy and flexibility that individual RCAs
required to transform practice day-to-day. The importance of this knowledge is widely cited in the literature as crucial to the development of PCC (Edvardsson et al., 2010; Kitwood, 1997; McLean, 2007b). Administration recognized the importance of promoting staff empowerment; however, evidence suggests that RCAs felt disempowered and marginalized. Findings suggest that although there was a staff hierarchy at Cedar Grove, with administration and nursing (RNs) staff unquestionably forming “top staff” (Jervis, 2002), power was also exercised laterally, and this was highly influential in the organization’s culture change objectives.

This study demonstrates the importance of Foucault’s (1978/1990) nuanced description of power toward fostering culture change. His assertion that power is exercised or produced (rather than possessed) through a “multiplicity of force relations” (p. 92) was clearly evident: “Power is everywhere; not because it embraces everything, but because it comes from everywhere” and, he suggests, it is “permanent, repetitious, inert, and self-producing” (Foucault (1978/1990, p. 93). Consistent with this, RCAs were seen to struggle with the complex interpersonal relations and micro-politics among their peers, where surveillance and power were exercised “over and against” (Foucault, 1980, p. 155) one another. As a result, although there was administrative support for a range of organizational policies, initiatives, and staff training to support the promotion of philosophies of culture change, power relations on the ground were seen to obstruct progress.

These fluid, lateral power relations played a strong role in shaping everyday life at Cedar Grove. For example, a care aide’s perception that she had to complete her assigned work per shift in order to “pull her weight,” in the eyes of her peers, highlights this
dynamic. This finding extends existing discussions on the topic by foregrounding the need to approach power relations in LTRC through a complex, multi-faceted lens. Furthering Kitwood’s (1997) contention that a “caring organization” needs to understand the relationship between “the way employees are treated by their seniors, and the way clients themselves are treated” (p. 103), this study suggests the need to consider day-to-day micro-politics between direct carers in order to achieve and sustain transformed care practices.

3) Finding the Right Message: “Serving Tea” as “Actual Work”

Data pointed to a tendency for the safety imperative and overall “busyness” (Tuckett, 2007, p. 128) of the institution to take precedence over the relational dimension of residents’ quality of life in this study. Cedar Grove struggled with how to promote relational care in a way that fostered uptake amongst direct carers and address these concerns. Given that personal relationships are fundamental to the workings of a care facility, it is perhaps surprising that there have been few studies conducted in which relationships are the focus of inquiry (Brown Wilson et al., 2009). This study contributes to this limited research by exploring some of the tensions that obstructed and issues that facilitated relationships between those who make up the care community.

In keepings with McLean’s (2007b) findings, relational care at Cedar Grove was challenged by perceptions within the organization of what constituted “the real work” of the care aide, that a direct carer who spent time relating to a resident might be seen to avoid the “‘real’ work” (McLean, 2007b, p. 183) of meeting a resident’s physical care needs. Lopez’s (2006a) ethnography identified care aides’ perception of resource limitations that might support these types of interactions as a barrier to culture change; he
found that managers were perceived as promoting practice that although good in principle, in reality was considered a sign that managers were out of touch and even “delusional” (p. 72). Borrowing form Banerjee and colleagues’ (2008) idea that “having coffee” is a representation of relational care in their study of Canadian and Nordic residential settings I raised the possibility of staff taking time to have tea with a resident. My suggestion was dismissed, and I encountered laughter.

Cedar Grove struggled with how to convey the message that relationships were crucial to the process of culture change. The tension between social care—“serving tea”—and physical care—addressing a resident’s fundamental need to, for example, use the toilet—points to the organization’s challenge to balance residents’ care needs. While my findings demonstrate the importance of foregrounding personhood through relational care, which can be effected even in small everyday interactions, they also suggest that good intentions are not enough to embed this belief in the direct care team. The quantitative findings generated through DCM provide a concrete way with which to convey the potential benefits of good dementia care when residents’ personhood is affirmed. Data showed that even brief (personalized) encounters had the ability to markedly improve the mood of residents. This was important information to staff because it helped them to see that even a small amount of time spent interacting with individual residents could have strong benefits and did not necessitate significant resources (time, energy). That staff were buoyed by the DCM data I shared with them underlines the important work that still needs to be done in getting the message out to all members of the Cedar Grove team. Many of the RCAs I met came to see, as Burgio and colleagues’
(2001) research shows, how they might employ communication strategies that improve residents’ well-being without devoting more hands-on time.

4) The Use of Resident Biography in Practice

When Augusta and Natasha independently responded to my greetings with the phrase “You know me?” they shared a widespread longing among residents for social recognition. Given research on risks of resident exclusions from meaningful social relations (Graneheim & Jansson, 2006), this finding highlights the importance of creating environments whereby residents might achieve meaningful social connections. Data show that staff and residents shared this sentiment. Staff did not feel they had the ability to properly incorporate personal knowledge of resident life stories into care practice. Staff wanted to know more about the people for whom they cared and how to use the knowledge they had to create personal interactions with residents.

Cedar Grove’s limited ability to construct what Baldwin (2008) refers to as a “narrative space” in practice is related in large part to the limitations of the RAI/MDS system with which biographical details are recorded. An important finding of this study regards the degree that organizational structures, such as the RAI/MDS system, can serve as a major impediment to personalized care. From a Foucauldian perspective, standardized processes prioritized the social construction of residents’ “official identities,” illustrating “the way that the gaze is formalized through standard assessment intended to be replicable and consistent between workers” (Grenier & Leonard, 2006, p. 103). The standard form of the RAI/MDS assessment tools meant that there was literally no space to record residents’ “small stories” (Baldwin, 2005) or narrative-based accounts that might counter the “official identity” by helping residents to
tell their story or helping staff to use these stories to see residents as people with skills or hopes for a future.

Data suggests that the RAI/MDS format/process access to residents’ biographical information in two main ways: 1) the type of information gathered, and 2) the required use of a computer interface. The practice of care planning via RAI/MDS exposed a digital divide in the care culture between those who communicated and documented electronically and those who did not. Not only was the format of “tick boxes” cited as hindering carers’ ability to obtain a sense of the “story” of the person in care, but a general lack of computer competency also limited care aides’ ability to contribute to or retrieve information from residents’ electronic charts.

These findings echo those from Kontos and colleagues’ (2009) research where direct carers cited electronic records as an obstacle to accessing residents’ personal histories and are important because they suggest how to further culture change at Cedar Grove. Of all LTRC staff, it is the care aides who spend the most hands-on time with residents. If this is the case, then it is important to recognize that computer literacy might be a crucial area of staff training and that all staff must have ready access to computer terminals. It might also be important to implement assessment tools and ways of documenting that allow staff to capture the uniqueness, or personhood, of each resident.

Due to the widely cited deleterious consequences of care that does not reflect the needs or concerns of the individual (Clarke et al., 2003; Coker, 1998; Kitwood, 1997; Vittoria, 1998), the digital divide that characterized the care culture has profound implications for its resident population.

With a growing number of residents with dementia and a limited number of
residents who had the benefit of involved family, the need to facilitate staff access to and use of biographical information is central to the quest for more personalized care. During my fieldwork I was able to identify several innovative ways that administration attempted to introduce organizational strategies meant to facilitate balanced care. One example was a staff program that called on carers to create and implement an initiative geared toward a resident identified as most in need of social connection. This initiative was meant to fit into carers’ daily schedules in a seamless manner; it was later evaluated through a performance dialogue. Similarly, the posting of resident biographies on doors was initiated to better integrate personal information into practice. Another strategy involved prioritizing RCA attendance at care conferences. These initiatives were in the early stages of implementation when I left the field, but together they suggest positive response to the types of concerns raised in my study. The need for further research regarding how well these kinds of strategies combat more structured tools for facilitating a ‘knowing’ of residents to facilitate person-centred care is identified.

**Fostering Relational Care Practices: Philosophical Considerations**

Some staff took advantage of the opportunities that existed in the day to meaningfully connect with residents. DCM’s use of Personal Enhancers was helpful in articulating the ways in which these staff went beyond routine care to engage with residents in ways that maximized the potential of improving their well-being. I noticed that some staff seemed more likely to offer care that was personally enhancing; those who did appeared to be more adept than others at relating to residents as people. Watching these staff interact with residents in ways that struck me as entirely positive, it seemed that they embodied caring – they seemed to *be* caring people. Although DCM
helped identify these practices, what characterized these interactions and made them stand out was hard to put a name to or quantify.

In my exploration of what mattered in the lives of the Cedar Grove community, I found that a desire for personal relationships was paramount. Above, I discussed obstacles that hindered the formation of relationships among various members of the organization’s care culture. In this section, I want to situate consideration of relational care in the context of philosophical approaches that add to our understandings of the interpersonal dynamics shaping long term care practice.

Thinking about how some staff were adept at engaging in relational care and others seemed challenged to do so attuned me to the fact that the process of culture change underway at Cedar Grove did not seem to draw on an identifiable set of ideals for caring. Although a code of ethics guides clinical nursing practice (College of Registered Nurses of BC, 2011), efforts to transform practice were not informed by a codified organizational ethical philosophy articulated as such. As discussed earlier, it is certain that care practice involved ethical decision-making, yet my exposure to informal or formal conversations around culture change did not include discussions around an ethics of caring that was accessible to RCAs. This is important because it points to the established connection in the literature between ethics and relationship in dementia care and an opportunity to initiate a positive approach. Hughes and Baldwin (2006) reference a feminist “ethic of care” to illuminate the relevance of ethical principles to how we relate to others. In their words,

Rather than being an autonomous, independent-individual, the Self is seen as related to and interdependent on others, connected through and responsive to the
needs of others as they arise in the messiness of real life. (Hughes & Baldwin, 2006, p. 76)

Specifically, what seemed to be lacking from organizational discourses was a moral or ethical approach to the kind of caring relationships administration hoped would enable staff to engage. McLean (2007b) points out the potential harm when an ethics of relational care is not at the forefront, stating, “when the relational dimension is missing, there can be no genuine care transaction, only action directed at accomplishing some instrumental goal” (p. 197). In the same vein, Brooker (2004) cautions, “Without a strong value base, the reason for using these tools in the first place becomes obscured and a slavish following of technique can occur” (p. 221). Both researchers offer critical insights into a LTRC setting undergoing culture.

In Chapter 7, I detailed the exchange between nurse Evelyn and resident Violet that demonstrated the nuanced social interactions, both verbal and non-verbal, that occurred multiple times a day in the care culture. Violet needed Evelyn in the moment and despite her other work responsibilities, Evelyn offered Violet the attention and support she needed. Kitwood’s (1994/2007) use of Buber’s (1970/1996) conception of “I-It” and “I-Thou” is helpful in understanding this and other care interactions that are at their root ethical in nature; they demonstrate the challenges I observed during fieldwork. Buber articulates two ways of being in the world that have relevance for dementia care. Buber’s treatment of the person-in-relation makes the important distinction between encounters that are based on intimacy and mutuality, involving two active subjects, versus those based on detachment, involving a subject and a passive object (Buber, 1970/1996). Whereas an I-It relation is unidirectional and based on “coolness,
information-getting, objectivity, instrumentality,” the I-Thou mode of relating necessitates, “involvement: a risking of ourselves, a moving out and a moving towards” (Kitwood, 1994/2007, p. 225). For Kitwood, who drew on Buber, this discernment might be summed up as follows, “to be a person is to be addressed as thou” (Baldwin et al., 2007, p. 175). The I-Thou is then an expression of a type of positive relationship between carer and resident and one that is effectively co-produced.

This consideration helps us understand how, in conventional care, for example, a person living with a dementia diagnosis, too often faces I-It encounters, which as they are described by Buber are inconsistent with true meetings (of carers and persons with dementia). Unfortunately, I-It modes of relating prevail in non-person-focused care settings. Kitwood (1994/2007) warns that despite the most thorough care planning and assessment, if care is based on an I-It mode of relating it likely obscures personhood, thereby limiting care interactions to largely biomedically-driven, task-based encounters rather than “meetings,” in Buber’s sense of the word. Following Buber’s conception of I-It or I-Thou, we might say that the verbal and the non-verbal interaction I observed between Evelyn and Violet was an example of an intimate exchange based on an I-Thou encounter, that is, it took place in the context of relationship. In the way they communicated with one another, it seemed that Evelyn was sensitive to Violet’s needs; Evelyn was able to put herself in Violet’s shoes and recognize that she needed prompt attention and social connection.

Both Sevenhuijsen and Kitwood highlight difference as an operational idea in their conception of ethical relations in care. Dutch ethicist Sevenhuijsen (2003) questions a carer’s ability to ever truly place themselves in “someone else’s shoes” and argues for
an understanding of what she calls “asymmetrical reciprocity” (p. 186). Exploring the relevance of a feminist ethic of care to recent Dutch social policy, she contends that an ethical relationship between the person giving and the person receiving care “begins with the willingness to be open to everyone’s unique, embodied subjectivity: the idea that everyone is positioned differently and leads an existence which cannot be reduced to that of others” (Sevenhuijsen, 2003, p. 186—emphasis added). Sevenhuijsen’s perspective is based on the recognition of difference—that we all have unique histories and lead varied lives. Moreover, she posits, our awareness of, or openness to, asymmetry in a relationship is a “gift.” Sevenhuijsen’s line of reasoning is similar to Kitwood’s influential definition of personhood, which has garnered significant debate in dementia studies (see page 19). Sevenhuijsen’s (2003) idea of the gift of ethical relations, the ability to be receptive to others, does not demand reciprocity, but rather, opens up possibility for “moral communication” through respect for difference. In this light, Evelyn’s gift of attention (a bestowing of care) to Violet, though their relationship may possess asymmetry, is given in the spirit of generosity, which Violet needed at that time and readily received. The encounter between Evelyn and Violet does not entail the paternalism and divisions that frequently accompanies caring interactions.

Following Levinas (1958/2009, 1984/2009), nurse Evelyn’s response to resident Violet is grounded in a sense of responsibility and moral obligation. Levinas also highlights the issue of reciprocity in caring relationships. Levinas’ consideration for the other suggests that motivations to care arise from a sense of duty or responsibility that does not “require symmetry and reciprocity” (Lavoie et al., 2006, p. 229). In practice, one person, in this case resident Violet, is arguably in a more vulnerable position, relative to
nurse Evelyn. Indeed, “that is what caregiving means: to take care of the other, not the other way around” (Lavoie, 2006, p. 230). This is not to say however that Violet lacks agency. Indeed, as this study found, and a limited but growing body of research has identified, there is strong evidence of persons with dementia as active agents in their own lives (Bartlett & O’Connor 2007, 2010; Brooker, 2004; Downs, et al., 2006; Graneheim & Jansson, 2006; Phinney, 2008). Rather, Levinas’ work offers insight into why (at least in part) Evelyn cares for Violet as she does—a moral calling to take care of another. It is through caring that Violet is supported to live her life, “to continue to exist whatever the challenge encountered may be, whatever the problem involved” (Lavoie et al., 2006, p. 233).

The exchange between Evelyn and Violet demonstrates the challenge of evaluating the nature of communication and attributes of relational care. Thinking more deeply about their encounter, the improbability of the nurse’s success at stalling Violet in her demands likely occurred to her. Evelyn spoke to resident Violet in a manner that suggested familiarity. Yet, she was direct and, if not for the bodily expression of warmth (holding hands), her approach might be construed as undermining Violet’s personhood through Kitwood’s (1997) Personal Detractors of ignoring and infantilization. Was this a care encounter based on a meeting of two persons, or did Evelyn’s pre-conceived notions (what Levinas refers to as non-intentional, pre-understandings that contributes to labeling and stigmatization) of resident Violet limit relational aspects of the exchange? Or, was this interaction personhood supporting because Evelyn demonstrated respect for Violet when she spoke with her as she would with any other adult, one without a dementia diagnosis? Perhaps, in Evelyn’s experience with Violet she knew that this was the best
way to communicate with her – in a direct way? Knowing Violet as I did, she seemed happy with the outcome that morning and welcomed the warmth of Evelyn’s hand as they left the nurses’ station and moved toward her room. For Evelyn’s part, although her paperwork was interrupted by Violet, her affect suggested she was pleased to help Violet meet her needs at that moment; Evelyn readily offered her hand to communicate reassurance to Violet.

Aside from demonstrating the complexity of ascertaining the relational in care, this example also illustrates one of the factors in LTRC research that has been suggested as a means to foster relationships between staff and residents; it pertains to the professional rewards of caring. That is, despite direct carers’ agreement that structural barriers hindered their ability to engage with residents at a relational level, the fact that many staff perceived relationships with residents as a significant reward of their job is important to consider in the quest for transformation of the care culture. As direct carer Sally movingly shared, “they make me a better person.”

This sentiment has been identified in an emerging body of research focused on the development of personal relationships in residential settings (Brown Wilson et al., 2009; Moyle, Muirfield, Griffiths, Venturato, 2010; Ryan, Nolan, Enderby, & Reid, 2004; Walsh & Shutes, 2012). Carpenter and Thompson (2008) identified the importance of direct carers’ capacities in “transcending the job” toward quality care. For participants, transcendence entailed meaningful work that surpassed the day-to-day responsibilities of care (“just a job”) to work that centred on “cherished relationships” (Carpenter & Thompson, 2008, p. 30). Ball and colleagues (2009) similarly contend that for direct carers, “relationships with residents are a primary, for some the primary, component of
job satisfaction” (p. 40). As Kitwood (1997) envisioned a paradigmatic shift in a care
culture—through the enactment of Positive Person Work—the goal of attending to
residents’ personhood, of caring for another in the context of relationship, has rewards for
both residents and carers. In sum, in spite of the myriad challenges carers faced, the
relational aspects of their practice helped some staff value the importance of social bonds.

Finding Meaning in the Everyday

There is consensus in the literature that meaningful activity and social
engagement are linked to the well-being of persons in various stages of dementia
(Harmer & Orrell, 2008). To discover what day-to-day life was like for residents who
experienced a care philosophy foregrounding the “person,” this study looked at what
residents “did” between rising and going to bed each day—“how residents actually spend
their day or how often they interact with others” (Ice, 2002, p. 348). It focused on
patterns of behaviour that residents exhibited during unstructured periods, as well as the
meanings they attached to them. I wanted to know how culture change was experienced
by those most impacted by organizational policies and practice. What made “life worth
living” (Brooker, 2008 p. 525) for the residents?

Given my professional practice and research history, I focused on unstructured
activity, which allowed me to work with my own institutional “familiarity,” rather than
“strangeness” (Coffey, 1999). This focus also helped highlight the implementation of
PCC principles into care practice. Thus, the following section discusses television
viewing and mealtimes as vital opportunities to work across a theory/practice divide that
has been indentified in recent PCC literature (Dewing, 2008; McCormack, 2004; Nolan et
al., 2002; O’Connor et al., 2007). In my study, these two unstructured activities provided
important foci to understand how individuals might maintain social routines that they
developed prior to entering care and which might continue to give their lives meaning. It
is important to note that both television viewing and mealtimes were already a part of life
at Cedar Grove, and I felt that they might be key points to explore culture change,
without undue strain on resources (time or money).

Cedar Grove’s ability to deliver structured programs to meet the needs of all residents and to effectively promote residents’ social engagement throughout the facility was limited by mix of social, physical and organizational factors. The physical structure of the facility required people to travel down an elevator to attend programs, deterring some residents from joining scheduled activities. Residents also expressed confusion around scheduling of events. Others, especially those who had more complex care needs including dementia, preferred to stay in the more familiar, calmer environment of their floor. As I have argued above, this situation was exacerbated by a commitment to “safety first”: “at risk” residents were restricted from venturing to other areas of the facility, meaning that a significant number remained on their own floors and were unable to attend structured programs.

This practice reflected a conflict between the changing needs of residents and the leisure program offered at the time. Persons with dementia are less able to initiate action, less able to have his or her psychological needs met through engaging in meaningful activity. Without creative solutions as to how to involve them in activities, persons with dementia are at great risk for social exclusion. Knight & Mellor (2007) found that although residents participated in social activities, they neither had their social needs met, nor did their “participation” correlate with the experience of social inclusion. I found that
resident participants required social connections that were “a far cry from afternoon bingo or a bus trip” (Knight & Mellor, 2007, p. 84). In my fieldwork, I identified a disparity between available activities and residents’ needs; structured activities were poorly attended suggesting a variance between resident needs and the kinds of programming offered. This led me to question, as Knight and Mellor (2007) and others do, whether programmed activities are capable of meeting crucial psychosocial aspects of care.

Unstructured, everyday activities promise to help ameliorate this gap. Residents talked about feeling a separation from things they used to do and a lack of continuity with a “normal” life. Rather than special (leisure) activities, they missed the flow of everyday chores and interactions. As Chaudhury’s (2008) exploration of memory, self, and home contends, we need to understand “place as process” (not simply a space or time) and that place-based processes are integral to individuals’ engagement in activities that create “the texture of daily life” (p. 31):

Our memories of place as well as our sense of self are saturated with experience of doing particular things in particular places—perhaps especially with the memory of routines we are hardly aware of as we carry them out everyday.

(Chaudhury, 2008, p. 31)

At Cedar Grove, I saw that residents longed for familiar quotidian practices; the absence of these routines interfered with their ability to feel at home or otherwise find meaning in day-to-day life. Not being able to participate in everyday activities—for example, not having the chance to make tea when one wanted to or tidy up the dishes—could be devastating to residents’ sense of self and their ability to see Cedar Grove as a home.
Television Use in Long-Term Care

Fieldwork highlighted the potential importance of television use as a vital unstructured activity in LTRC. For many people watching television is a key part of daily life, and thus might provide a powerful site for developments in research and practice. Yet, the issue of television use at Cedar Grove exposed aspects of the care culture in relation to hierarchy, power, and resistance. Differences surfaced around culture members’ opinions on what the appropriate use of television for residents might be, especially for persons with dementia. Some direct carers were of the opinion that residents craved aspects of so-called normal life and that the lack of access to television on the SCU added to their sense of institutionalization. Ironically, this was the problem administration sought to avoid with their decision to remove cable access television from the SCU. Given direct care staffing levels and limited leisure staff hours, carers maintained that the television provided at least something to do in the absence of scheduled leisure programs. Conversely, administrators’ viewed the presence of television on care floors to be in conflict with the type of social milieu they sought to create.

Findings from this study suggest that television might be seen to give residents’ lives meaning. However, when I talked about television with administrators, my suggestion that it might be an interesting point of focus was met with unease and apprehension. This unease mirrors a larger societal correlation of television viewing with social disengagement. Although television watching plays a significant role in the leisure activities of North Americans, its use in the area of dementia care is poorly understood.
There is a widespread tendency to dismiss television watching as a less than meaningful activity, despite its ubiquity in contemporary social life. It is hard to dispute the fact that a significant portion of most Canadians’ daily life is spent watching television. Research indicates that since the 1950s, older adults spend more time than younger people watching television (Van der Goot, Beentjes & Van Selm, 2011). Today, television is omnipresent and by implication, culturally significant. Indeed, Statistics Canada (2004) states that women aged 60 years and over watched on average 36 hours, while men watched 31 hours per week of television.

Despite the centrality of television in the life of adults without dementia, there is a dearth of research on the use of television by persons with dementia (de Medeiros, Beall, Vozzella, Brandt, 2009; Heller, Dobbs, & Strain, 2009). In this literature, there is a focus on the negative or harmful effects of television in a residential care context. This research considers television viewing to be a passive, solitary activity that at its best contributes to boredom and at its worst is a possible trigger for agitation and other behaviours associated with dementia. Television viewing is also seen as a mode of surveillance, a means to allow a small number of staff to monitor large groups of residents and to otherwise refrain from engaging them in meaningful activity (Meyer, Dorbacker, O’Rourke, Dowling, & Nicholas, 1992; Wood, Harris, Snider, & Patchel, 2005). Indeed, a family member commented how she was disturbed by what she considered to be the “optics” of “parking residents” in front of the television, adding that she felt it was related to insufficient staffing.
Armstrong-Esther, Browne and McAfee (1994) note that persons living in residential care often are relegated to “sitting clean and quietly” rather than participating in the “major goals of adulthood such as activity, independence and interdependence through engagement” (p. 271). These investigators found that residents with and without dementia spent much of their day sleeping in front of the television rather than watching it, citing the television’s “sedative effect” on viewers (p. 269). This finding was also noted by Wood and colleagues’ (2005), who found that SCU residents spent as much as 21% of their day in front of the TV with no indication that they were actively engaged with it or one another. De Medeiros and her research team (2009) also found that “dozing” was the most common activity for residents “watching” television. Interestingly, these researchers observed no disruptive behaviours associated with residents’ viewing TV.

Other innovative research explores positive uses of television in dementia care by investigating the viewing interests of persons with dementia. It looks at how television viewing can be modified to meet the needs of older persons, with promising outcomes. A part of a growing body of research is geared toward video programming and computing technologies for their therapeutic potential. For example, Heller and colleagues (2009) found that “cognitively congruent” television and video programs that are less complex (employing a simple story line and slower, more obvious presentation of material) could be engaging for persons with dementia. Waller (2007) offers a unique suggestion to improve control for the person with a dementia’s through an “individualized TV channel” (p. 126) which shows the person’s favourite shows all on the same channel. Other multimedia-based projects described in the literature are dual purpose: they are intended
to both offer persons with dementia therapeutic benefits accrued by, for example, reminiscence and entertainment, while at the same time they attempt to offset the multifaceted demands placed on carers in both informal and formal settings. Examples of such media-based interventions include Video Respite (Hall & Hare, 1997; Heller, Dobbs, & Strain, 2009), a “simulated presence” intervention for people in distress called Personalized Video Channels (Kajiyama, Dib, Tymcuk, Boxer, Olinsky, 2007), and an interactive life story multimedia project called Memories of Life (Cohene, Baeker, Marziali, & Mindy, 2007). These interventions display people’s life stories through visual/audio presentation via analog tapes or digital media in an attempt to capitalize on this everyday ubiquity of television and increasingly screen-based media. The reminiscence-based CIRCA program (Purves et al., 2011) is another similar example, except its focus is on shared socio-cultural memories.

Thus, the research that has explored the use of television in the care of adults with dementia suggests mixed findings and uses. Most often though, in practice it appears to have at least some negative connotations; the image of older people lined up, often asleep, in front of the TV set which stirs criticism and contempt, and rightfully so. However, during fieldwork the time I spent with a core group of Juniper Way residents watching television revealed a complex social activity at play. My fieldwork for example suggested that Reality TV, which evoked the greatest response from residents, might provide a valuable means for reminiscence. Reality TV, a genre that exploded in popularity in the 1990s, relies on “‘ordinary’ people to live their lives in front of television cameras” (Oullette & Murray, 2004, p.6). It is a phenomenon that draws from both documentary and soap opera (Reid, 2007). I noted that “Hoarders: Buried Alive”,

337
“Wife Swap”, “How Clean is Your House,” and “Supernanny” were the television shows that residents favoured. After watching these shows with them, I realized that these programs shared common characteristics that rendered them accessible to persons with challenges associated with age and dementia. In general, the shows I watched addressed two “cases” per show and feature individuals coping with personal, domestic challenges. Many of these shows featured an authoritative “talking head” that explained the various situations—someone speaking directly to the camera against a white backdrop. The simplicity (and repetition) of the story line combined with pared-down visuals appeared to assist those with hearing, visual, and/or memory deficits to follow the thread of the story.

Reality TV shows purport to present to viewers “real life” problems that in most cases deal with issues of familial or domestic nature; they offer “nonscripted access to ‘real’ people in ordinary and extraordinary situations” (Oullette & Murray, 2004, p. 2). Often, a “specialist” is brought in—for example, a psychiatrist, expert house cleaner, or childcare specialist—to offer solutions to the participants’ problems. Generally, each show ends on a note of redemption whereby the situation is resolved to the betterment of all—the home is returned to order and the bad parent regains domestic control. As Oulette and Hay (2008) explain, “Reality TV invests the minutiae of everyday life with dramatic importance” (p. 8). Observation of residents’ behaviour during these sessions highlighted several benefits: First, it was this apparent accessibility of the everyday, domestic portrayals of family life that the residents appeared to connect with, and evaluate. For example, as residents tusk-tusked, shook their heads, and laughed at the characters on screen, viewing these scenarios permitted audience members to engage in
acts of (downward) social comparison, which, given their current life circumstances, were rare opportunities.

Second, watching Reality TV provided residents with a rare opportunity to be experts. This finding calls to mind what the literature on Reality TV points out: that these shows capitalize on the Foucauldian notion of panoptic vision toward the creation of good citizens (Oullette & Murray, 2004). It was significant that residents, who were themselves objects of the gaze, could use viewership to project the gaze onto others. This gaze was manifest in their responses and judgments of characters in relation to a perceived norm. Borrowing from Oullette & Murray (2004), I might argue that I saw how Reality TV produces an “unstable text that encourages viewers to test out their own notions of the real, the ordinary, and the intimate against the representation before them” (p.6). The value of this for residents with dementia was apparent.

In addition to the active engagement with the content and the benefits to mood that residents accrued through interactions with each other, a third related gain was that watching TV entailed a social experience wherein residents were gathered in a small group. People appeared to enjoy the social encounter of being together in front of the TV; there was a sense of conviviality and a vital levity as residents watched television together. Despite the newness of the Reality TV genre developed here, the simple act of watching television allowed individuals to take part in a socio-cultural practice that had likely always been a part of her life.

Findings on residents’ use of unstructured time revealed that for some, television viewing occupied a significant portion of their day and that more may be going on than initially meets the eye. Further research is needed to examine the structure of viewing and
content of television programs and to suggest how television use might be made more functionally relevant in the social care of persons with dementia.

**Dining and Person-Centred Care**

A second important unstructured activity in the life of the LTRC facility revolved around regular meal times. For better and worse, residents’ days were organized around food and eating. Beyond the obvious nutritional importance of eating, food clearly had social significance in residents’ daily life. This investigation identified the potential of mealtimes to encourage resident engagement, enhance social networks, and foster a positive social milieu—as they have done across their life course (Hopper, Cleary, Baumback, Fragomeni, 2007). As Malloy (2012) asserts, mealtimes are times of the day that for some residents entailed the greatest contact with staff.

As part of the recent culture change, administration was focused on shifting the way food was served to both fulfill their mandate and improve the social and physical environment. Efforts toward the creation of an improved dining experience on the SCU had been deemed by administration to be a success. Reducing noise/chaos and fostering of a more relaxed environment paid off in the healthful weight gain of residents who had previously been agitated by the milieu and as a consequence were under-nourished. As well, staff was assigned rotating duties—helping residents eat, cleaning up, serving, and so on. My fieldwork occurred at the tail end of these changes in care practices around food and meal time; the observational data generated post-changes highlighted that residents still rarely lingered over a meal, with most meals taking 15 or 20 minutes to complete. This suggested a missed opportunity, because as data show meals are social opportunities; residents’ affective states did not always improve during these interactions.
These are important points to consider in light of the important social function that food sharing serves in supporting social connectedness (Savishinsky, 2003). This finding might suggest a shortage in staffing levels as well as a need for training in this aspect of dementia care. As with other care interactions, staffing levels have been shown to influence residents’ eating, because those requiring assistance to eat might not be given the attention needed. Murphy’s (2006) review of research in this area identified positive outcomes for residents who required direct care help eating when there is a ratio of 1-2 residents per staff. This is significantly higher than at Cedar Grove suggesting that the pressures on staff at mealtime might detract from the time they might spend interacting with residents over a meal or facilitating sociability between residents.

Manthorpe and Watson (2003) highlight the importance of food in the well-being of persons with dementia, and they suggest the need to consider meals and eating within the broader context of activities and ordinary life. Despite facing budgetary and staffing challenges, the organization was still able to include food at celebrations. For example, Christmas treats and St Patrick’s Day cookies helped create a festive atmosphere for these seasonal events and the more frequently held unstructured social gatherings like pubs and coffee times. These parties attracted residents from other floors, as well as families and friends in a way that other activities did not, serving to foster social inclusion through relationship building across care levels in the campus of care. I discussed earlier the stigma associated with the SCU. I found that parties held on Holly Street were instrumental in demystifying life there and breaking down barriers between “them” and “us.”
Toward Social Inclusion

During fieldwork I was struck by residents’ demonstrations of “social cognition” (Sabat & Lee, 2011) that offer important insights into dementia care capable of supporting social inclusion. Social cognition has been described as “the ability to interpret other people’s faces and facial expressions, their tones of voice, posture” (Adolphs, 2005 as cited in Sabat & Lee, 2011, p. 318). These abilities, among others, are important to communication and social situations and were clearly demonstrated by residents. Often these interactions entailed a mix of modes of communication, both verbal and non-verbal and included various indicators of well-being, such as showing affection, bodily relaxation and initiation of social contact (Brooker & Surr, 2005). Residents often walked around hand-in-hand, hugged one another, sang together, chatted, or responded to each other in caring and affectionate ways. In contrast, most signs of residents’ ill-being, such as withdrawal, agitation, and bodily tension (Brooker & Surr, 2005) were rooted in isolation and/or a lack of activity or interactions with anyone or anything. These findings are important because they underscore the well-documented link between a lack of stimulation or social connections in a person’s environment and challenging behaviours. More than this, these findings challenge stereotypical (deficit-focused) depictions of the dementia experience, which have too often served to excuse substandard living environments for persons with dementia. This information challenges organizations to recognize residents’ social abilities and need to enjoy meaningful relationships and to make this a priority. This conclusion has important implications for culture change and restructuring of care practices at Cedar Grove. The success of Cedar Grove’s
transformation hinges on its ability to recognize and address residents’ need for relationships and direct carers’ abilities to support this fundamental human need.

In these concluding paragraphs I would like to discuss directions for social inclusion. The fact that many residents spent a significant portion of the day disengaged from the world around them was widely acknowledged by culture members, and it troubled them. This study, in addition to developing understandings of spatial and relational dimensions of care, provided opportunity to explore temporal aspects of the care culture. The methodology of ethnography allowed me to grasp just how much of a resident’s day was spent “busy doing nothing” (Nolan, Grant, Nolan, 1995). Dementia Care Mapping further highlighted the temporality of residents’ day-to-day inactivity. Specifically, it allowed me to quantify the time a resident spent dis/engaged from his or her environment while also pointing to ways to support engagement and thus improve well-being.

Importantly, the use of DCM and its dependence on temporal aspects of care had a profound impact on me as a researcher and therefore the findings and scope of this study. DCM demands concentrated observation of the mapper over time, and so, sitting in a common area mapping, for example, an immobile resident with dementia who had not interacted with anyone for 5 minutes, then 10 minutes, then 35 minutes was difficult to witness. The ability of DCM to illuminate not only interpersonal care, but also the social environment is key. In this study, I came to more fully appreciate how engagement and activity are not just about caring differently, but also are a product of staffing levels. The issue then is not solely one of interpersonal skills on behalf of the RCA, but rather, a lack of opportunity to connect and engage residents. In consideration of the current social-
economic climate of LTRC, which is defined by a scarcity of resources (time, money, staff), my findings help shed additional light on the barriers to achieving PCC that have been identified in research (Innes, 2006; Knight & Mellor, 2007; Leibing, 2006; Scott-Cawiezell, 2005; Tuckett, 2007).

I recognized that resident inactivity was a significant challenge, the implications of which were evident in the concerns expressed by staff, administration and family members. Administration wanted to bridge periods of inactivity that existed between islands of care and structured events. A key part of the culture change process was rooted in a commitment to increasing social engagement through reconsideration of “leisure” programming and addressing the disparity between the existing activity programming and residents’ social-psychological and physical needs. There were several reasons for this disparity that included the relegation of social activity to the sole purview of leisure staff and inadequate nursing care levels. It was also noted that because of the nature of their positions, leisure staff were unable to provide coverage for residents’ 24-hour need for socialization. Eden Alternative principles, with their focus on alleviating boredom, helped inform organizational priorities for culture change around activity. It was understood that residents were in general under-stimulated.

The leisure programs residents enjoyed shared similar characteristics: they were loosely organized, allowing the person to come and go while providing opportunities for socialization. “Coffee time” and “pubs” were informal in nature, style, and structure and suggest what many residents are looking for in their day—social interactions with peers in a relaxed atmosphere. This want or need is in conflict with the job descriptions and standardized assessment forms that currently define and evaluate social engagement. For
residents with more advanced dementia, data exposed several instances whereby residents’ well-being improved through access to stimulating, everyday materials that were provided during unstructured periods of the day. For example, one day near Halloween, I observed a volunteer place carved pumpkins on the mantle in the common room of the SCU. Seeing this, resident Fran rose immediately from her chair, crossed the room, and proceeded to spend some time poking her fingers in the pumpkin’s eyes, nose and mouth. She was clearly enjoying herself. Other behaviours of this kind occurred without the direct assistance of staff. I observed similar self-directed and spontaneous interactions between residents and the floor’s cat in the early part of my fieldwork. Importantly, these types of interactions by residents counter many of the negative assumptions that surround dementia and the presumed abilities of people who live in an SCU. These types of engagement do however require some facilitation. Creating an environment that makes possible unstructured activity throughout the day requires the provision of resource materials (magazines, newspapers, books, flowers, hobby materials, music).

Research on meaningful activity offers insight into these findings. Phinney and colleagues’ (2007) exploration of the meaning of activity found that individual’s preferences for activity remain stable across the life course, even after a dementia diagnosis. These researchers speculate that a person’s ability to maintain involvement in the things that they once enjoyed provides a critical sense of continuity in the present. Tapping into residents’ past roles, interests and routines is vital to creating meaning in activity and fostering engagement in persons with dementia (Cohen-Mansfield et al., 2010; Harmer & Orrell, 2008). As Cohen-Mansfield and colleagues (2010) assert, “many
people have folded towels in their life, but not all have played with dolls or an expanding sphere” (Cohen-Mansfield et al., 2010, p. 552). In this light, it might be that pubs, coffee times, watching television, or looking at the newspaper offer participants the thread of familiarity, and therefore meaning, that other programs, like shuffleboard, trivia, or arts and crafts, might not. This claim is also supported by other findings in this study in which residents expressed longing for activities they associated with “home,” such as listening to the radio, watching TV, reminiscing with friends and family, eating, doing the dishes, and reading the paper.

Of the two floors that were the focus of this study, the SCU was further along in modifying social care to include space, time, and materials for unstructured activity. Given the link between inactivity and negative behaviours associated with dementia (Cohen-Mansfield et al., 2007), understanding activity (structured or unstructured) as a means with which to lessen use of physical or chemical restraints is critical information. In the SCU, music and horticultural therapy were supplemented with the availability of everyday sources of leisure, like newspapers, knitting baskets, and clothes for folding. In spite of the presence of dementia in most of these residents, the less structured “un-program” appeared to help meet residents’ day-to-day need for stimulation and human connectedness. Ensuring residents’ access to everyday activities represents a vital means to support residents’ autonomy and citizenship. This finding builds on Barnes and Brannelly (2008) ethics of care analyses where the quest to ensure residents retain the ability to take part in activities that they see as personal meaningfully is an important aspect of their continued “competence” (p. 390).

As an aspect of citizenship, investment in social inclusion for residents through
meaningful occupation, leisure endeavours, and creative activities represents a fundamental right (Cantley & Bowes, 2004), and is an important ingredient in the drive to achieve ethical care and social justice for persons with dementia. Empirical data from my study adds to knowledge production in the area of dementia, activity, and social inclusion. Findings emphasized the importance of everyday social activity as a key ingredient in residents’ well-being, elevating it to the forefront of person-centred LTRC. In sum, in addition to recognizing the potential of everyday activity to contribute to residents’ quality of life, staff require the material resources and organizational policies necessary to enable persons with dementia to engage in activities. These resources are essential to culture change and I argue are as vital as medical care to one’s quality of life in a residential setting.
CHAPTER 10:
CONCLUSION AND STUDY IMPLICATIONS

The timing of this study was fortuitous. When I set out to study how a person-centred approach in a long-term residential care setting might shape the lives of the people that lived and worked under it, I could not have foreseen the unique opportunity that was presented to me. A few months into my fieldwork, the organization ended its formal affiliation with the Eden Alternative. This was a significant institutional decision and it allowed me to witness and be a part of an unexpected and fascinating transformation of Cedar Grove’s culture of care. As I have detailed in previous chapters, Cedar Grove considered “the person” in care to be fundamental to their practice. Yet, in part because of this, they no longer felt compelled to retain an “official” person-centred care status or endorsement, such as that offered by the Eden philosophy and approach.

At the time, I had several questions about how this shift would impact my research. I had begun to generate data and was in the early stages of getting to know people and how things were done, and I was not sure what this shift would mean to my study. After consultation with my committee and others, and much consideration, I became increasingly excited by this development and the opportunities it presented. Because I was not concerned with a program evaluation of Eden per se, my initial research objectives remained pertinent. More than this the unforeseen change would allow me to focus on person-centred care as an evolutionary process. Obviously, the organization’s withdrawal from Eden did not occur overnight, and the consequent shift in
substantive care practice was not immediate. Moving forward in relation to person-focused practice remained foundational to the organization; so the break from Eden was a significant change and one that added new questions and lines of inquiry to this investigation. For example, it led me to question of how Cedar Grove would define itself—to itself and to others—post-Eden. I was interested in what category of culture change model this long-term care facility would find connection to and seek guidance from in its emergent development. Did Cedar Grove need to follow a particular model, a brand name, or franchised approach as they moved forward? Or was the organization capable of making its own informed decisions about person-centred care. These questions and other concerns became central to my attempt to understand this organization’s approach to culture change.

The process of charting a new direction also intrigued me. Research on culture change often addresses a shift in philosophy of an organization from traditional care to another specified model. Often, the two approaches are discussed as polar opposites; in between, there is a discussion of the transition period. If progress is achieved it is toward an established end point, as in “we now offer [_____ fill in the blank] care.” In these descriptions, the transformed culture of care will be measurably better than the previous approach, once reached. This line of reasoning reminded me of a vital point on organizational culture and its transformation offered in the work of Baldwin and Capstick (2007). Regarding Kitwood’s dichotomous description of “old” and “new” cultures, they assert:

The likelihood is that any real world care setting will share indicators of both cultures rather than belonging to one or the other, and that any change which is
brought about will be gradual and contingent, dependent on a multiplicity of variables, many of which are unpredictable. (2007, p. 266)

Cedar’s Grove’s break from the Eden Alternative also helps to foreground a change in the larger context of care in Canada. What has occurred progressively over recent years and what is predicted to continue in the future at Cedar Grove, as with other LTRC settings, is the trend toward residents who generally have more acute health care needs and who are frailer and less mobile than they have historically been. The portion of the resident population with dementia will increase. The ethno-cultural diversity already evident in the staff profile will grow in the resident population as the their profile begins to better reflect the diversity of the broader urban community it is part of. In this context, Accreditation Canada (ACC) guides Cedar Grove development. In addition to meeting ACC standards for quality improvement in relation to safety and a variety of staff and organizational assessments, Cedar Grove’s goal to further humanize care rested on an amalgamation of influences. The shift away from Eden needs to be understood in relation to Cedar Grove’s efforts to keep “the person” at the centre of care in the shifting terrain of LTRC.

Study Implications

The following five points convey the practice and methodological implications from this exploration of a culture of care that continues to prioritize the “person” as it transforms itself, and how this culture constructs daily life for its members. These points serve as a conclusion; they summarize this study’s findings and point to vital directions for future investigations.
Overcoming Organizational Barriers—Employing an Intersectional Perspective

Part of the Cedar Grove’s development involved anticipating the needs of future cohorts of residents. To this end, my research suggests that an intersectional approach might assist in furthering relational care practice by drawing attention to sites of power, oppression and marginalization. This study noted that the resident population, the majority of whom had some level of dementia, was still relatively homogeneous in relation to gender, language spoken, culture, and economic status. Most were of European decent and spoke English as a first language. The direct care team was largely composed of women of colour from a diversity of ethno-cultural backgrounds. These ethno-cultural differences between residents and care staff, while characteristic of many LTRC settings in Canada, will need to be addressed in future research. As resident profiles change, new challenges will arise.

Demographic predictions for the organization revealed projections for increased diversity in relation to culture, race, sexual orientation, faith and gender, in future cohorts. An intersectional perspective will be instrumental as the facility prepares to provide optimal care for an increasingly diverse resident population (gay/lesbian, ethnically diverse). With the knowledge that certain people are relatively more privileged in care settings, Cedar Grove might then further challenge taken for granted assumptions about resident populations and increase the ability to ameliorate structural inequalities in the organization and, in so doing, to understand and improve the lives of increasingly heterogeneous groups of residents.
Valuing Everyday Activities—Supporting Well-Being and Social Inclusion

Findings from this study emphasize the importance of everyday social activity as a key factor in residents’ well-being. This supports well-established gerontological literature that argues that there is a strong association among activity, well-being, and social inclusion. At the time of data generation, the organization’s ability to foster social inclusion through activity was limited—contrary to its positive intentions. For many residents, the activity program presented a barrier to engagement. In fact, the focus on traditional leisure-type programming and entrenched work roles among staff, as well as the challenging staff-resident ratios, contributed to long periods of inactivity in a resident’s day. The quest to combat institutional boredom and the ability of the organization to foster social inclusion requires that residents have increased access to meaningful, unstructured activity. This is particularly relevant for residents of the SCU who require a greater degree of attention and support to achieve even basic levels of social inclusion.

Residents at differing levels of cognitive ability expressed the desire to participate in everyday activity and decision-making. Residents wanted to participate in activities they enjoyed and were familiar with; often, these activities were associated with “home,” such as listening to the radio, watching TV, reminiscing with friends and family, eating, and reading the paper. Another aspect of inclusion relates to residents’ participation in everyday decision-making. The opportunity in care to exercise one’s autonomy through making everyday decisions, such as what clothing to wear, when to eat, or what to do with spare time, is fundamental to residents’ quality of life. Data from this study suggest
that residents crave the thread of familiarity that unstructured activities and decisions on everyday matters enabled.

In the SCU, observational data showed that residents’ access to material objects like flowers, newspaper and magazines, hobby materials, and also music, were beneficial to their engagement. People were not only found to independently interact with these materials, but they also stimulated interactions (passive and active) between residents and with staff. Occupational or work-related types of activity such as folding aprons, clearing tables, and sweeping also improved residents’ well-being. Although one-to one interaction with residents with more advanced dementia is generally considered optimal, seasonal celebrations were also effective at increasing these residents’ social engagement. Through these gatherings, residents participated in a choice of activities such as dancing, eating, and socialization in a format that was accessible to residents with a range of abilities and interests. Critically, these events also fostered feelings of connection and community. These research findings underscore ways to further social inclusion in dementia care settings.

Residents had diverse experiences in relation to activity and social inclusion. Residents with involved family enjoyed greater access to life outside the facility. Similarly, residents with the financial means to employ a private companion were supported to access wider communities, within the facility and beyond. Importantly, a private companion also enabled a resident to obtain vital one-to-one social contact and to be more engaged in larger group activities than they would otherwise have been. Mobile residents were better able to independently access activity and social interactions, despite the presence of dementia.
Pleasure and enjoyment are rarely considered to be crucial aspects of life in care and they are hard to quantify in evaluations of care settings. Yet, they are vital to caring for and maintaining personhood. It is incumbent on researchers and carers to find ways to increase residents’ pleasure and enjoyment day-to-day and is important to organizational policy and practice. My data show that this area of research is significant and warrants future investigation in relation to social inclusion.

**Supporting Relational Practice**

Culture change in LTRC rests on a shift from a focus on instrumental, task-based care to ethically grounded relational care that supports the personhood of residents and staff alike. This study revealed the vital importance of relationships (resident-resident and staff-resident) to the well-being and quality of life of residents and as a driving force behind carers’ commitment to their work. In general, residents expressed a lack of meaningful social connections in their daily lives. Data at the interpersonal level showed that residents longed for conversations and personal connections with direct carers as well as with other residents. This study highlights several organizational barriers to relational care: these include the nexus of time constraints, workload, and resident acuity. Although administration supported flexibility in work roles as a principle of management and a fundamental aspect of the organization’s philosophy of care, the cultural beliefs of direct carers in conjunction with current job descriptions suggest impediments to this type of flexibility, which is an essential part of person-centred practice.

Also, although low staff-resident ratios negatively impact the ability of staff to engage with residents at a relational level, data also reveal that staff interactions with residents alone were not enough to improve residents’ affective states. For people with
more advanced dementia, Dementia Care Mapping showed that interactions that were personal in nature (i.e., involved biographical details or that appealed to personal preferences) and contained verbal and non-verbal expressions of warmth and connection were most likely to improve residents’ well-being. This finding indicates that improved staff-resident ratios, though vital for culture change initiatives, alone are insufficient to sustain relational practice. Efforts to transform practice might also benefit from a codified organizational philosophy articulated around an ethics of caring that is accessible to RCAs. In sum, these identified barriers point to key sites for practice development. It is important to note too that at the macro-level, present day staff-resident ratios, which amount to approximately just over 2 hours of staff-resident interaction per day total, continues to be a critical structural obstacle to relational care.

Using Biography in Care Practice

Residents, understood as active citizens in the culture of care, should have the right to choose the way they want to live. Biography represents a vital means to help secure these rights by foregrounding the “person” in care and helping to articulate residents’ everyday needs and preferences and in so doing, supporting residents’ well-being. Thus, biography is essential to person-centred practice because it has the potential to support personhood, to shed light on current behaviours, to increase residents’ participation in decision-making, and to lay the groundwork for relationships in care to flourish. In light of these and other established benefits, organizational structures are needed to increase the capacity of direct carers to integrate biography in practice.

Findings outlined in this study point to a number of barriers around staff access to and use of biographical information in practice. At present, residents’ biographical
information is gathered in care plans that are generated through the standardized process of the RAI/ MDS. Data highlight that this system creates structural barriers that hamper direct carers’ use of residents’ biographical details: 1) computer literacy, 2) limited access to electronic care plans, and 3) a lack of time allocated in a shift to this purpose.

Data show that greater access to standardized electronic care plans alone will not necessarily familiarize carers’ request with residents’ personal stories. Findings point to the inherent problems with the current electronic form and the kind of information collected as obstacles to the use of biography. Staff discussed the format (check-lists) in which information on residents’ past lives and personal preferences are recorded, and they suggested that this interferes with their ability to discover the “story” of the person behind the resident. Staff spoke fondly of the (old) paper charts and use of narrative-based accounts, which they saw as being better able to capture and transmit the details of the resident in an accessible way. As the use of portable digital devices emerge in practice, for example, hand-held digital devices like the iPad or other tablets, there will be opportunities to rethink and revise the type and form of information gathered. This might allow staff and administration to address significant barriers to uptake.

To ameliorate potential problems, we might look to the work of Baldwin (2008), who describes the process of narrativity, the sharing of our personal stories, as a performative activity that supports personhood. For Baldwin, this performance occurs interpersonally, in and through the stories we tell about ourselves, and those stories that others tell about us. Linking the personal with the political, Baldwin advocates for the structural integration of resident biographies within an organization so that care practice can move beyond mere appreciation to a “narrative citizenship” (2008, p. 224).
keeping with Baldwin’s work, this ethnography identifies biography to be fundamental to the citizenship rights of residents and as a fundamental issue for practice development. This focus is particularly important in light of demographic trends present in the Cedar Grove population, toward greater numbers of older people without supportive familial networks and the increased prevalence of dementia. Although biographical approaches have a proven ability to support family engagement in care, this study found that a significant portion of the resident population lacked familial participation in their care. This reality challenges the organization’s ability to obtain and use residents’ biographical information, especially for residents with dementia. Findings, thus, point to the need for future research in the area of person-centred care and biography in the absence of family.

Structural changes in the organization must take place in order to capitalize on the benefits of biography in care. Future research is warranted on alternative means to assist in the gathering and transmission of this population’s biographical stories in order to make them useful to staff and in care plans.

**Mobilizing Knowledge—Toward Person-Centred Care Practice**

Dementia Care Mapping and other types of observational methods that take into account the context of behaviours of persons with dementia are crucial to understanding the transformation of care. The ability to involve persons with dementia in research that impacts their lives is an underlying goal for gerontological research. To date, the vast majority of research on how best to accomplish this objective has relied on qualitative interviews with people in early stages of dementia. This involvement often necessitates proxy consent for people in more advanced stages of dementia. Because at a certain point in the trajectory of dementia people typically experience challenges in verbal
communications and cognitive abilities, alternative methods of accessing this population’s opinions and preferences vis-à-vis quality of life and care practices need to be considered.

In this ethnography, participant observation and Dementia Care Mapping were instrumental in my ability to gain insight into non-verbal expressions of personhood and bodily, affective communications between residents and their social and physical environment. These methods allowed me to access verbal and non-verbal communications between residents and staff during care interactions. Dementia Care Mapping in particular was instrumental in the transmission of research findings to direct carers for the purposes of identifying what aspects of practice worked well and encouraging discussion around what aspects of care might move person-centred practice forward. DCM findings helped shed important light on residents’ everyday life by exposing aspects of residents’ experiences of their psychosocial environment as well as the nature and number of care interactions within a mapping session. Emerging findings presented to staff participants highlighted the ability of even brief social interactions to increase the mood and engagement scores of residents of the SCU. This finding was constructive because it provided opportunity for staff to discuss and reconsider their own practice. Specifically, staff talked about a reluctance to engage with residents at certain points throughout the day because they assumed that for interactions to be positive, they had to be lengthy. In this climate of limited staff resources, the result of this cultural belief was to avoid some interactions altogether.

DCM helped to translate the benefits of meaningful personal connections between staff and residents that did not entail significant staff resources in terms of energy and
time. The mobilization of this research to practice in this way points to the ability of DCM to convey positive practice implications in an accessible format that fosters uptake. Future research on observational tools toward more person-centred practice is needed in the current fiscal climate as the prevalence of dementia in resident populations increases and external pressure for good care continues to grow.

Balancing Needs: Working to Keep “the Person” at the Centre of Care

This ethnography helps illustrate one of the many trajectories the objective of culture change can take. It is unequivocally the story of a process. Along the way, philosophies of care intermingle with regulation and policy. The legacies of Eden remain in varying degrees and other person-centred research and influences in LTRC are added to inform staff development and organizational policy. There seems to be a common understanding grounding this process: residents deserve the best possible physical and social care. In addition, there is a tangible conviction that all direct carers do important, skilled work and that they deserve optimal working conditions, appropriate training, and support as their needs shift alongside those of the residents they provide care for.

Responding to increased numbers of residents with greater care needs, as well as to significant external forces, ACC has begun to assume a larger role in shaping organizational policy. ACC dictates that resident and staff safety must be a bottom line in practice decisions, and in part because of this requirement, the organization deemed the Eden Alternative to be wanting. It could not fulfill the institution’s needs on its own. The safety imperative also includes collective safety, evident in public health measures such as the use of quarantines to limit the spread of infectious agents. Cedar Grove considers the direction of ACC necessary to enable them to fulfill the organization’s mandate to
provide community members with a safe living and working environment. For the organization, ending affiliation with Eden provided more freedom in their response to the current LTRC climate, at micro-, meso-, and macro-levels. At the same time, Cedar Grove considered the ACC guidelines to be an insufficient independent guide to help further the organization’s social care objectives, in particular, for people with dementia. To this end, leadership decided to incorporate and implement a variety of approaches and interventions to steer staff skills training and development toward person-centred practice. My fieldwork and participation in staff development contributed ideas to this mix. Taking from Eden what made sense to them in terms of their organizational needs and adding to this base these other influences, Cedar Grove continues to work toward being leaders in LTRC.

The situation at Cedar Grove allowed my to study person-centred culture change in action. Empirical findings on the process underway revealed other key aspects of culture change. By and large, I found that administration led the process. Staff was involved in constructing the change, but it was largely driven from the top. Leaders’ vision of optimal care was passed down to frontline carers and shaped practice development; constituent groups took up this vision in varying degrees. Staff members were at different points along their own developmental path, both personally and in relation to the organization, and their entry into the cultural change was disparate. Some staff seemed happy to experience change in expectations and work roles and were able to enjoy the idea of new challenges; others seemed bent on retaining the old ways at all costs. Still others were resolute and seemed to be willing to hold on until the new wave passed, as they expected it would. Organizational structures, such as union-based job
descriptions, remuneration, and staffing levels, remained (relatively) constant. These challenged the organization’s ability to be flexible and agile, and were widely identified by administration to be fundamental to culture change. It is also important to note that not all administrators were uniformly comfortable with the new direction.

Families are also on this journey. However, their somewhat limited involvement in the life of the facility meant that it was difficult to see the extent to which this change might impact them.

While residents’ involvement in this process was crucial, the roles that they might play were less clearly defined or understood. Residents were impetus for the change; however, except for a minority, they were largely passengers on the journey. My stated goal for this study was to find ways of joining with residents and sharing in their lives; I set out to learn from them and to gain insight through ethnographic methods into what made a difference to people in their life. From residents, I came to understand how important interpersonal relationships and activity, in the broad sense of the word, were in the move toward the experience of social inclusion. Cedar Grove understood the connection between well-being and activity, and a large part of its cultural transformation rested on finding ways to facilitate “being with” residents and a desire to foster engagement in the life of the facility. Residents demonstrated their need for connection through action or they eloquently communicated what was important to them day-to-day, as well as what troubled them. Throughout my fieldwork and data analysis, I was deeply affected by the experiences and voices of residents. It is my sincere hope that their voices reverberate throughout this study and ultimately contribute to wider discourses on LTRC practice.
The ongoing process underway at Cedar Grove is complicated. It is marked by tensions and conflicts, as well as harmonious interactions, between culture members who are at varying degrees of self-awareness and commitment and who come to accept their part in supporting its transformation. Fundamentally, residents’ medical and social needs drive this process, which continues through the writing up stage of this study. They underline the implications for this study developed in the section above, particularly as it extends to gerontological scholarship on person-centred practice and research.
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APPENDICES
Appendix A: Site Photographs

Corridor – Holly Street
Resident’s Room – Cedar Grove

Terrace, Holly Street – Cedar Grove
Sitting Room – Juniper Way

Activities Schedule Notifications – Juniper Way
Holly Street - Resident’s Room – Velcro Barrier

Today’s Menu

Cedar Grove Sample Menu
Appendix B: Research Poster

THE UNIVERSITY OF BRITISH COLUMBIA

a place of mind

Study Title: Person-centred care in long-term residential care

My name is Elizabeth Kelson. I am a doctoral student at the University of British Columbia. I am here to learn about person-centred care (PCC) from the community. Through this research I hope to better understand PCC from the perspective of Elders, their family members and/or friends, care staff and volunteers. You can find me spending time on and observing daily life and talking with people about their experiences. I am really excited to be here!

This study has received ethical approval from the University of British Columbia Behavioural Research Ethics Board (BREB).

If you would like to participate in this study, or have any questions/concerns please feel free to contact me at:

Elizabeth Kelson, Ph.D. (c), Interdisciplinary Studies, UBC
email: elizabeth.kelson@ubc.ca or by phone: 

I am working under the supervision of the following:

Dr. Deborah O'Connor (PI), Prof., Social Work, Dr. Alison Phinney, Assoc. Prof., Nursing, UBC
Dr. Habib Chaudhury, Assoc. Prof., Gerontology, SFU

CRPD Centre for Research on Personhood in Dementia

Dec 2009-Dec 2010
Appendix C: Presentation Evaluation Form

Staff Group Meetings Presentation – Evaluation Form

Was the information presented useful to you? Please describe.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If so, how will it impact your work?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Did the presentation raise any ideas that you would like to know more about? Please describe in a few words.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Is there something about your work that I got wrong or did not seem to understand? Please explain.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix D: Sample DCM Chart

% of time BCC recorded - 24 hours map - Holly Street - SCU

Behaviour Category Coding

A – Articulation – interacting with others verbally or otherwise – with no obvious accompanying activity
B – Borderline – being engaged but passively (watching)
C – Cool – being disengaged, withdrawn; not watching any activity; sitting silent and slumped, not relaxed
D – Doing for self - engaging in self-care such as putting on clothing, tidying clothes, combing hair
E – Expressive – engaging in an expressive or creativity activity such as singing, dancing, art work
F – Food – Eating or drinking
K – Kum & Go – Walking, standing or moving independently in a wheelchair
L – Leisure – Engaging in leisure, fun and recreation
N – Nod, Land of – Sleeping or dozing
O – Objects – Displaying attachment to or relating to inanimate objects like handbags, clothing, dolls
P – Physical – Receiving practical, physical or personal care
U, Unresponding – Attempting to communicate (verbal and non-verbal) but not receiving a response
W - Withstanding – repetitive self-stimulation of a sustained nature (not outside of self)

14 (University of Bradford, DCM 8 User’s Manual, 2005)
Appendix E: Sample Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA

Consent to Participate – Family Members

**Title:** Person-centred care in long-term residential care

**Principal Investigator:** Dr. Deborah O’Connor Ph.D., RSW  
Professor, School of Social Work, UBC

**Co-Investigators:** Dr. Alison Phinney, Ph.D., RN  
Associate Professor, School of Nursing, UBC

Dr. Habib Chaudhury, Ph.D  
Associate Professor, Department of Gerontology, Simon Fraser University

Elizabeth Kelson Ph.D. Candidate  
Interdisciplinary Studies Graduate Program, UBC

**Purpose:**  
The purpose of this study is to better understand how person-centred care functions in long-term residential care. As a family member or friend of a resident of [redacted], you are being invited to take part in this research because your experiences are vital to understanding how person-centred care works on the ground. We are seeking input from family members or friends with first-hand experience of person-centred care. This knowledge will be used to help describe a person-centred culture of care and to inform care practice. This research is being conducted in partial fulfillment of a Doctor of Philosophy degree, Faculty of Graduate Studies, University of British Columbia.

**Study Procedures:** If you take part in this study, you will be asked to take part in interviews (at least 2) focused on your perceptions of person-centred care as well as your perceptions of your relative’s (friend’s) daily life in long-term residential care. Each interview will be scheduled at a time that is best for you. The interview will be in the form of a conversation that will last approximately one hour. Each interview will be audio-recorded and transcribed.

January, 2010
Your participation in this study is voluntary and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions and to withdraw any information you do not wish to be included in the study. Withdrawal or refusal to participate will in no way jeopardize your relative’s (friend’s) care.

Since we are trying to get as full an understanding as possible, if you were agreeable, the student researcher (Elizabeth Kelson) will also review your family’s members’ chart in order to obtain the details of the resident’s medical needs (for example, their diagnosis) and to understand the documentation process in person-centred care practice.

Potential Risks: There are two main risks to taking part in this study. First, it is possible that you may feel upset, embarrassed or tired by thinking or talking about your experiences. If you become distressed, we will stop the interview immediately upon request. Also, we will be available to help you locate appropriate support if you find that you are distressed by the interview. Second, we will not be able to guarantee confidentiality around your participation. To help ensure that your participation remains confidential, we will remove all identifying information from any documents or reports about this research, so that others outside of [redacted] will not recognize you. However, we cannot ensure that others at [redacted] are not able to identify your input. Other attempts to insure that your participation remains confidential includes identifying you only by a pseudonym and storing files that may contain identifying information about you in a secured location separate from other documents. All documents, audiofiles, and digital photographs will be stored on a computer hard drive that is password protected and accessible only to the research team listed above.

Information obtained from you (with identifying information and names removed) may be used for educational purposes or for presentations at scientific conferences.

Potential Benefits:
Although you will not derive any direct benefit as a result of your participation, it is sometimes nice to know how important your thoughts and experiences are to others. We are expecting that this may offer one way to make sure your thoughts and opinions are heard and used to develop high quality care. Also, people sometimes find it helpful having someone listen to them as they describe their experiences. Finally, participants may benefit from a feeling that they are contributing to research focused on an area that is of interest to them.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact Dr. Deborah O’Connor at [redacted] or [redacted], or Elizabeth Kelson at [redacted] or [redacted].

Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at [redacted] if long distance e-mail to [redacted].

January, 2010
Your signature below indicates that you have received a copy of this consent form for your own records. Thank-you.

Sincerely,

Deborah O'Connor

Elizabeth Kelson

Your signature indicates that you consent to participate in this study.

________________________________________   _________________________
Subject Signature                        Date

________________________________________
Printed Name of the Subject signing above

January, 2010